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ABSTRACT

Presented is the 1975 report of the President's Committee on Mental Retardation which examines the issues in the field and sets national guidelines for public education and prevention. Eleven chapters are included on the following topics (sample subtopics are in parentheses): issues in mental retardation (biomedical and social-psychological prevention); future projections and their implications with respect to possible governmental initiatives (integration of human service delivery); legal rights of the retarded (objectives for the attainment of citizenship status); objectives and courses of action to ensure the right of every child to be born well (health delivery system); objectives for reducing the incidence of mental retardation associated with social disadvantage (equal educational opportunity which encourages cultural differences); objectives for the attainment of humane service systems (availability of a personal representative); objectives pertaining to international cooperation for the resolution of the mental retardation problem (international assistance programs); objectives to improving public attitudes (public education to promote understanding); governmental objectives for insuring the effective use of public resources in mental retardation programs (coordinated and comprehensive planning of federal, state, and local efforts); program costs and results (advantages of continued investment in pilot and demonstration programs in early childhood education); and a chapter outline of goals, objectives, and recommendations. Case studies are provided as illustrations throughout the text. (SB)

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Report to the President

Mental Retardation: Century of Decision

President's
Committee
on Mental
Retardation

March 1976

Washington, D.C.
20201

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* Term expired May 1975.
** Resigned April 1975.

Letter of Transmittal

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
WASHINGTON, D.C. 20201

The President
The White House
Washington, D. C. 20500

Dear Mr. President:

When this Committee met with you last, you encouraged it to proceed with a report that would project the nation's needs in the prevention and treatment of mental retardation through the year 2000. The Committee has worked hard and long on this formidable task, and presents its essential findings in the pages that follow. Further background can be found in additional volumes, as explained in the Preface.

What emerges from this document is a problem that is massive and multi-faceted, but with many of its parts susceptible to solution if we apply what we know. Other parts seem likely to yield to further research. Still others appear linked to our success in dealing with the broader problems of disadvantage in our society.

Very clearly, mental retardation is a problem we cannot ignore. It directly affects some six million retarded Americans, almost as directly involves millions more in their immediate families, and in the long run touches us all.

The Committee has looked at the problem with awareness that, important as it is, it is not the nation's only social problem, and that it cannot make unlimited demands on limited resources. The Committee finds, however, that much can be accomplished through better use of what is now available, and makes the important point that investment in prevention and human development, if wisely planned and administered, can earn significant national dividends.

Every dollar for prevention of mental retardation could save many times that amount in costs of long-term care. Developing the capabilities of the mildly and moderately retarded persons who account for 95 percent of the retarded population could result in productive citizens who would contribute to the economy. Whatever the degree of retardation, changing wasted existences to meaningful lives is a human benefit beyond price.

The job that needs to be done will demand the best efforts of State and local government and private agencies, in cooperation with the Federal Government. We submit this document in the hope that, under your leadership, all departments and agencies of the Federal Government will re-examine and strengthen their roles. Even more broadly, we hope you can use it as the foundation for a call upon all Americans to accept and assist their retarded fellow citizens.

As you have so eloquently said, "With our understanding, they will thrive. With our love, they will flower."

Faithfully yours,

David Mathews
Chairman

Enclosure

Preface

The Executive Order establishing the President's Committee on Mental Retardation directs it to report to the President annually.

For 1975, it is offering a report more ambitious in scope than any in its 10-year history. The Committee has attempted to project the nation's needs in mental retardation through the year 2000.

"Mental Retardation: Century of Decision" puts forth recommendations arrived at by the full membership of the Committee in the course of many sessions over a period of more than a year. In developing these proposed national guidelines for the next quarter-century, the Committee sought and obtained the views of a broad cross-section of persons both within the mental retardation field and from other disciplines that could provide insights. While the report is thus representative of some of the best thinking available on the subject, the Committee itself takes sole responsibility for all statements made.

The report will include at least four volumes, of which this one represents the core. To get a comprehensive background for the recommendations in this volume, readers are directed to the others in the "Century of Decision" series.

Already published is "Mental Retardation: The Known and the Unknown," which for the first time presents a picture of present knowledge and areas of ignorance concerning this widespread condition.

To be published later in this bicentennial year is a volume which reviews the historical shifts in our treatment of retarded persons, and assesses where we stand today.

Rounding out the series will be a report on programs of the States, with an update of an earlier report on Federal programs under consideration.

The present book is a call to action on a wide front. Its recommendations relate not only to the Federal Government, but to all levels of the public sector, and the private sector as well. While many of them require the action of organizations or agencies, they do not ignore the power of the dedicated individual to help retarded persons achieve their rights and discharge their responsibilities. Interspersed in the text are vignettes which remind us we are dealing with the problems of real people, although their names have been changed.

We invite full discussion of the report in every kind of forum, from service clubs to legislatures. The report will be a failure if it is thought of as an end in itself. It will be a success if it serves as a starting point in many new efforts to make life better for those who happen to be retarded, and to increase the chances of a good life for those yet unborn.

Truly, this is the Century of Decision--and the decision is ours to make.

N. Lorraine Beebe

N. Lorraine Beebe,
Vice Chairperson
President's Committee
on Mental
Retardation

Acknowledgements

In this major project, the Committee received invaluable assistance from many sources, including, of course, the Committee staff. Principal credit, however, for research and writing of this volume and one of a historical nature to be published later must be given to DR. HENRY COBB. His devoted labors went far beyond all expectations, and demonstrated the professionalism and sound judgment for which he is highly respected by his fellow Committee members.

The vignettes of retarded individuals preceding most chapters are based on interviews by ROBERT PERSKE; the accompanying illustrations are by MARTHA PERSKE. If these pages successfully set the stage for the more formal portions of the report, it is because of the Perskes' sensitivity.

The Committee was significantly stimulated in its thinking about the kind of world that retarded persons may face in the year 2000 by the "futurists" assembled by Plog Research, Inc. Their names are listed at the end of Chapter 2.

Leaders in the mental retardation field who generously contributed their time and thought to the Committee's effort include DR. JULIUS COHEN, Deputy Director, Institute for the Study of Mental Retardation, University of Michigan; DR. GUNNAR DYBWAD, Professor, Florence Heller Graduate School, Brandeis University; ROBERT GETTINGS, Executive Director, National Association of Coordinators of State Programs for the Mentally Retarded; DR. JENNIFER HOWSE, Director, Willowbrook Review Panel; EDWARD L. JOHNSTONE, Consultant; DR. CURTIS KRISHEF, Associate Dean, School of Social Welfare, Florida State University; PAUL MARCHAND, Director, Governmental Affairs, National Association for Retarded Citizens; DR. ARTHUR NOWAK, Associate Professor, College of Dentistry, University of Iowa; DAVID RAY, Director, Arkansas Department of Social and Rehabilitative Services; DR. PHILLIP ROOS, Executive Director, National Association for Retarded Citizens; DAVID SOKOLOFF, A.I.A.; DR. GEORGE SOLOYANIS, Executive Director, American Association on Mental Deficiency; DR. DONALD STEDMAN, Chairman, Division of Human Development, University of North Carolina.

Experts from specialized fields voluntarily assisted the task forces into which the Committee divided itself to formulate recommendations. The task force on Full Citizenship and Legal Rights (Chapter 3) received help from MARCIA BURGDORF, Assistant Professor of Law, University of Maryland; DENNIS HAGGERTY, ESQ., Philadelphia; DR. MICHAEL KINDRED, Assistant Dean, College of Law, Ohio State University, and GEORGE NAZARETH, past president, Rhode Island Association for Retarded Citizens.

The task force on Biomedical Prevention (Chapter 4) drew on DR. MICHAEL BEGAB, Head, MR Research Center Program, National Institute of Child Health and Human Development (NICHD); DR. DAVID B. COURSIN, Director of Research Institute, St. Joseph's Hospital (Lancaster, Pa.); DR. GEORGE N. DONNELL, Chairman, Department of Pediatrics, U.S.C. School of Medicine and Physician-in-Chief, Children's Hospital of Los Angeles; IRENE FORSMAN, Assistant Professor of Pediatrics (Genetics), Los Angeles County-U.S.C. Medical Center; DR. RUDOLF HORMUTH, Specialist in Services for Mentally Retarded Children, Health Services Administration, HEW; DR. JOSEPH K. INDENBAUM, Medical Director, Olive View Hospital (Van Nuys, California); DR. MERRILL S. READ, Center for Research for Mothers and Children, NICHD; DR. NANCY W. SHINNO, Instructor of Pediatrics (Genetics), Los Angeles County-U.S.C. Medical Center; DR. GEORGE TAR-

JAN, Professor of Psychiatry, University of California Neuropsychiatric Institute; DR. THEODORE TJOSSEM, Program Director, Mental Retardation Branch, NICHD; DR. WINSLOW THOMPKINS, Consultant in Obstetrics and Gynecology, Health Services Administration, HEW; DR. PAUL TORRENS, Chairman, Division of Health Services and Hospital Administration, University of California School of Public Health; and DR. ROBERT TRANQUADA, Director, Central Health Services Region, Los Angeles County.

The group dealing with Environmental Prevention (Chapter 5) profited from the help of DONALD BARTLETTE, Consultant in Retardation-Vice President, Minority Affairs Coalition; DR. RUTH DIGGS, Head, Department of Special Education, Norfolk State College; DR. JAMES GALLAGHER, Director, Frank Porter Graham Child Development Center, University of North Carolina; DR. ROBERT GREENE, Assistant Vice President for Academic Affairs, Virginia Union University; DONNA JONES, Assistant Principal, Cuyahoga County Board of Mental Retardation; MRS. CURTIS KNIGHTON, President, D. C. Association for Retarded Citizens; DR. LEONARD W. MAYO, Chairman of Advisory Board, Developmental Disabilities Technical Assistance System.

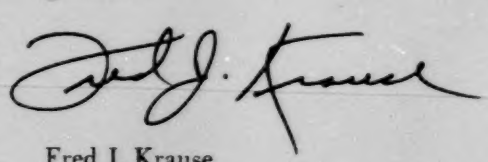
The Humane Services task force (Chapter 6) consulted with DR. ROBERT ELKIN, Peat, Marwick, Mitchell and Company; DR. DONALD H. JOLLY, Director of Research and Training, Pennsylvania Office of Mental Retardation; DR. GARY J. MAKUCH, Special Consultant for Right to Education, Pennsylvania Department of Education; JAMES McCORMICK, Program Director, Portage County (Wis.) Mental Health Service Board; DENNIS POPP, Coordinator, Developmental Disabilities Services, Kansas Department of Social Welfare.

WILLIAM RUDER, President of Ruder & Finn, Inc., provided stimulating ideas to the task force on Public Attitudes (Chapter 8).

And at regional forums conducted by PCMR with the assistance of HEW regional offices to obtain grass roots input, representatives of organizations too numerous to mention voiced views which were considered in preparing this report.

The encouragement and support of STANLEY B. THOMAS, JR., Assistant Secretary of HEW for Human Development, is gratefully acknowledged.

To any persons we have inadvertently omitted, our apologies. And to all who helped make possible the completion of this massive undertaking, our deepest gratitude.



Fred J. Krause
Executive Director
President's Committee on
Mental Retardation

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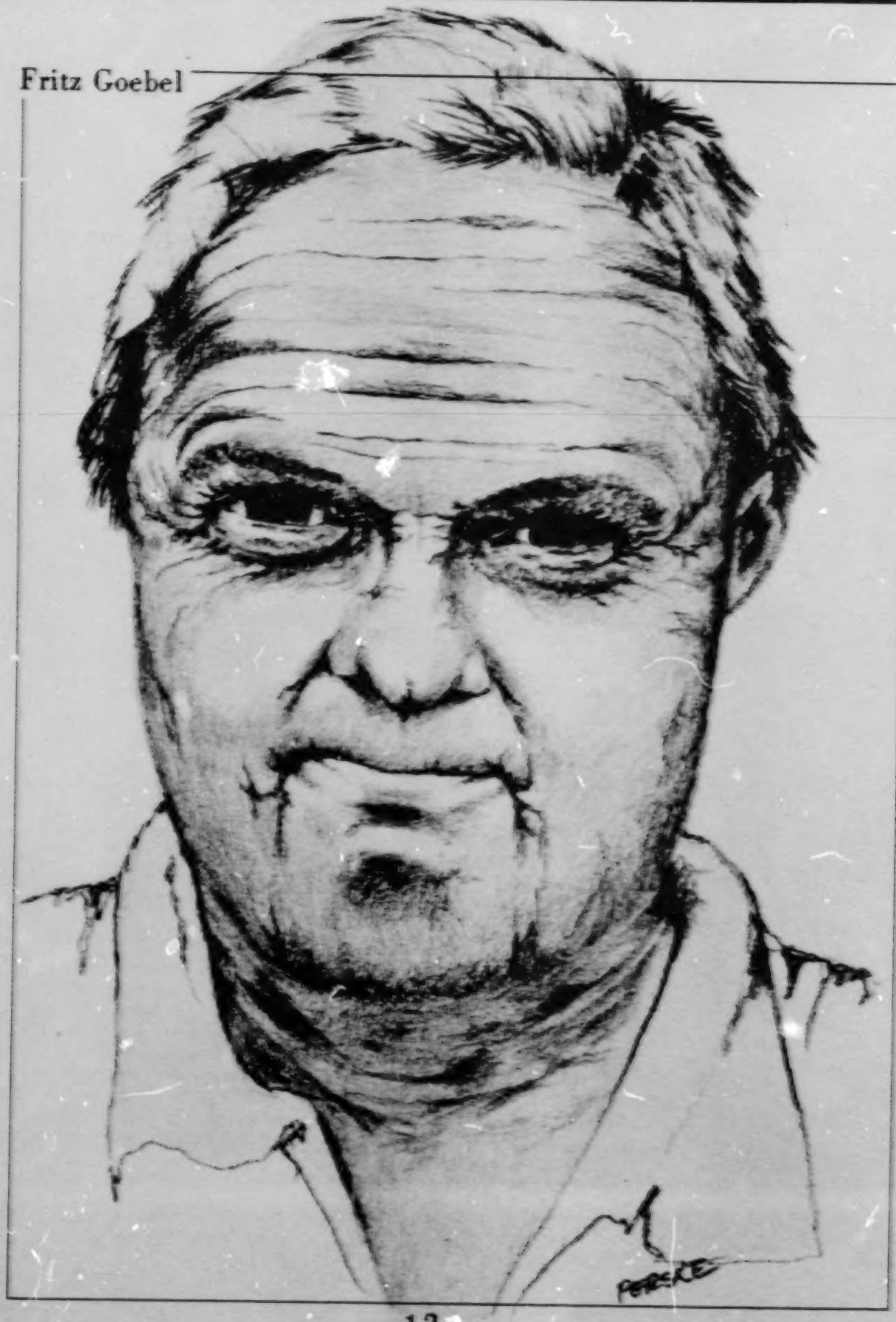
Fritz Goebel



"After three months at the home, Mr. Goebel developed into a rather attractive elderly gentleman."

"A lot of people pull away from those who become elderly. When a person is old and mentally retarded *at the same time, it's even worse. That's the case with Fritz. He needs people to interact with him. The day there's no one around who cares, he's finished."*

This is the way a sensitive young counselor sized up the situation of Fritz Goebel.

When Fritz was born in 1924, the physician told Adolph and Marta Goebel their son was "a mongoloid and a moron." He wouldn't live very long. They were urged to place him in an institution and forget him. The parents declined the advice. If Fritz was going to die, he might as well do it at home.

He grew up in the environment of the auto salvage business in a small southeastern Texas town where his father worked in the yard and his mother managed the office. As a small child, Fritz occupied a playpen near his mother's desk. Later, he roamed the yard with his father.

Although Fritz had no formal education he learned to recognize every car on the road. With imperfect speech, he could name anything from a Ford to an Essex. He never learned to read or write, but he used his own screwdriver and pliers to help his father dismantle auto parts. He never worked independently, other than bringing things to his father or mother. On some days he became obstinate and refused to do anything. Citizens remembered his friendly, happy way of walking up to customers, putting out a pudgy hand and greeting them with a handshake. He was remembered for the way he could mimic people's actions and mannerisms. This brought laughter from others. He liked that.

As Fritz grew older, his world became the whole town. He walked everywhere. He bought Cokes. He watched league play at the bowling alley, and he was in the bleachers for the town baseball games. He liked small children, and he liked petting dogs. Some ridiculed him, but he never seemed to feel the full force of such acts. Everyone had known Fritz from the time he was a baby and no one had any great fear of him. He merely happened to be different and was valued for the person he was.

In 1965, Fritz's mother and father were killed in an automobile accident. Fritz was sent to the State institution, which immediately transferred him to a 300-bed nursing home in a town 75 miles to the north of his home town.

After 9 years at the nursing home, Fritz was found to be in a deteriorated condition. He was without teeth. The medical record emphasized a heart condition —which he always had. He was diagnosed tubercular until it was learned that scar tissue on his lungs came from many bouts with pneumonia. Another notation placed emphasis on the "early aging of mongoloids," and he had "infantilized to the point of aggressive destructiveness, even the smearing of fecal material."

Then he was sent to a group residence for five men, where the care was highly individualized. After 3 months at the home, Mr. Goebel developed into a rather attractive elderly gentleman. Episodes of destructiveness and smearing ceased. He received enough personal attention so it wasn't necessary to seek it in those ways. A list of Mr. Goebel's skills was compiled, even though no one was sure how many of these things he did before his admission to the nursing home. The list contained the following:

- Prints name.
- Prints 15 simple words.
- Knows the names of all major candy bars.
- Can make variations of change amounting to 25¢.
- Utilizes coin-operated laundry equipment.
- Cleans own room (although all furniture is moved out of the

room and back in the process).
- Prepares simple meals (i.e., sandwiches, soup and instant coffee).
- Washes and puts away dishes.
- Knows his way on the buses and while walking (someone still goes with him since his attempted friendliness with children and adults is misunderstood).
- Handles all bathing, toileting, and grooming skills.
- Carries out the trash.
- Deposits letters in the mailbox on the corner.

Mr. Goebel has new dentures, eyeglasses, and a hearing aid. He likes the dentures, but refuses to wear the eyeglasses or the hearing aid at the present time. He has befriended one of his four housemates who also has Down's syndrome. He has developed a close relationship with the staff supervisor, a midd'e-aged widow. On her days off, he keeps asking when she will return.

Mr. Goebel attends a vocational training center, but finds it hard to stay at his piecework station. Often he falls asleep. Because of this, individual staff members were scheduled to stop at his work position once an hour and provide stimulation and personal reinforcement. The staff agreed to try this for a 3-month period. If this plan fails, other approaches will be attempted.

An aunt and two cousins from his home town visit him regularly. On two occasions he returned to the town and stayed overnight with the aunt. Plans are being made for him to be with them for the holidays.

Mr. Goebel is 51. At birth he was given a label and was expected to die early. With the aid of his parents and the attitudes of a town, it didn't happen. At the nursing home he suffered setbacks, many of which were overcome at the group home. Those close to him feel his developmental journey is far from finished.

Chapter 1

Issues in Mental Retardation

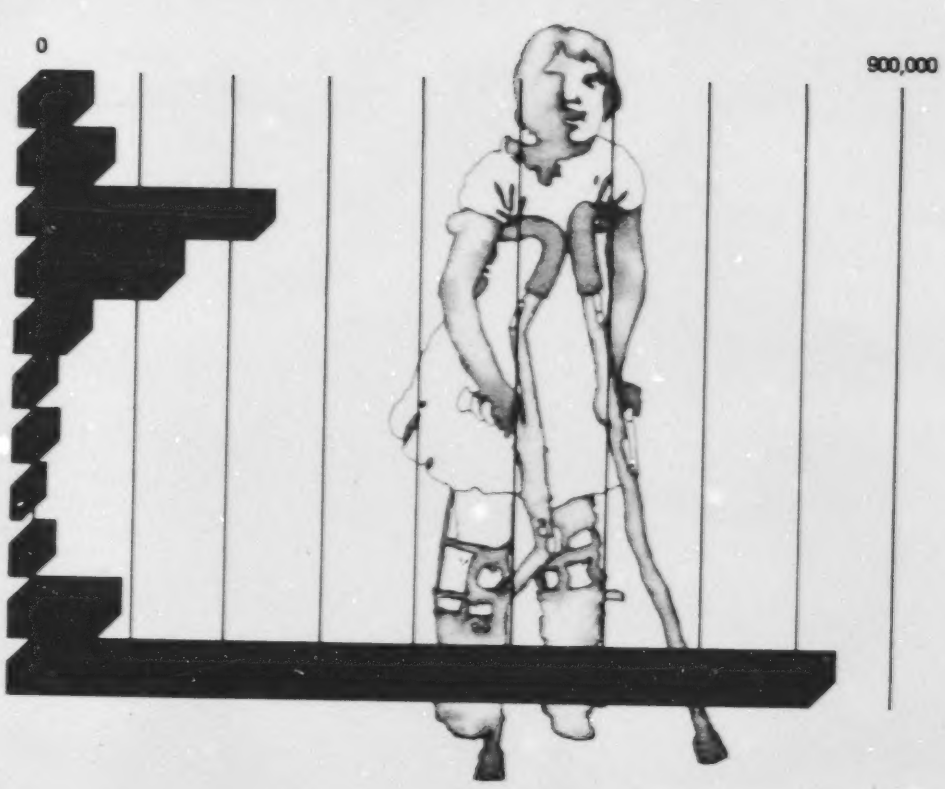
"The sought-for goals are to prevent mental retardation from occurring and to enable people who do suffer from this condition to live the most satisfactory, socially productive lives possible."

Mental retardation in 1975 is a pressing national problem. Some would say our handling of it is still backward, in spite of remarkable progress during the last 25 years.

Prior to 1950, the public had largely rejected from the human scene people who were mentally retarded. They were regarded as at best a hopeless burden and at worst a threat to safety and decency. Public policy sought to control the occurrence of retardation by preventing retarded persons from reproducing themselves; and to "protect" society by segregating and isolating them in mass-care institutions. Identification and classification of retarded children were dominated by observation of gross defect at birth or by a simplistic psychometry which measured the IQ when the child entered school. Little confidence was placed in the educative process, especially for those of more than mild or borderline disability. Undercurrents of a more understanding, humanitarian, enlightened and optimistic view of retardation, although developing slowly, were finding only scattered and sporadic expression in practice. Virtually the only resource available to relieve a family of the burden of care for a mentally retarded member, or a community of the threat of a "public nuisance," were custodial institutions which had become unbelievably overcrowded, dehumanized, repressive and exploitative.

In 1975, the emphasis of public policy is on developing the potential of retarded persons by early identification and intervention through education, social habilitation, and vocational training. The rights of retarded citizens as members of society are increasingly being recognized. Institutional care has been somewhat improved in quality, and less frequently resorted to; new patterns of care within the community are developing. Understanding the range and complexity of causes of retardation has resulted in some progress in preventing it. A variety of public health, social service, educational and habilitative service programs, financed by public and private funds, has become an increasingly prominent feature of community organization. Federal and State laws have been revised to protect the rights and provide for the well-being of mentally retarded persons. Extensive public information efforts, through all available media, have measurably increased public understanding and acceptance of mentally retarded people and the problems of retardation.

Estimated Incidence and Prevalence of Selected Birth Defects, U.S.A., 1975



Source: The National Foundation/March of Dimes.

These changes in public attitudes and practices have occurred in a context of concern for other human needs. Contemporary society, despite its chronic and unresolved problems of poverty, crime, discrimination, social disturbance, conflict, war, inflation, recession and unemployment, has moved steadily toward greater provision of social services, increased protection of human and civil rights, expanded health care, fair labor practices, social insurance for old age and disability, and a host of other measures to provide more equitable opportunity for all citizens. This has been at great financial cost; but the cost-benefit balance is not one-sided. Many believe that the cost of preventing or alleviating human problems is less than the cost of suffering under them. Where the balance should properly be struck has been a major political issue throughout this century.

The long-run expansion of the American economy, in spite of wars and periodic depressions, has been accompanied by a rising standard of living, increased longevity, expanded educational opportunity, reduction in incidence of absolute poverty and a shift in the division of the labor force from predominantly goods production to predominantly services production. The last quarter-century has been a period favorable to investment in major human problems of health, education, and welfare.

Currently, however, the United States, along with most of the other countries of the world, is encountering serious problems of inflation, unemployment, shortages of energy and certain raw materials, and other economic difficulties. Critical questions are raised with respect to the continuing ability of governments to expand or even to sustain current investments in

High School Graduation Rate: 1946-1975

Source: Bureau of Census and Office of Education.

human services. Serious question is also raised as to the top-heaviness of government. Can it manage its expanded operations without undue wastage, inefficiency and diversion of benefits to a proliferation of bureaucratic middlemen? Many of those involved in the delivery of services which government supports and regulates find themselves frustrated by the entanglements and inefficiencies of the official machinery.

While the Federal Government has greatly expanded its role in public and social services, the States and municipalities, as well as private organizations, have done so at even greater rates. As a consequence, both public and private sectors at all levels now face critical situations with regard to costs and problems of efficient management. Competition for funds becomes acute and financing of mental retardation programs precarious.

The incentives are strong to cut back the government's involvement, or at least to slow the growth of service functions, to reduce or compact the layers and proliferations of the bureaucratic structure, to shift the burden of effort from Federal to State, local, and private funds and manpower.

What course is taken will depend on a balance of what is desired and what is possible. In the following chapter, we shall explore possible future

Median Family Income:
1947-1974
(1974 constant dollars)

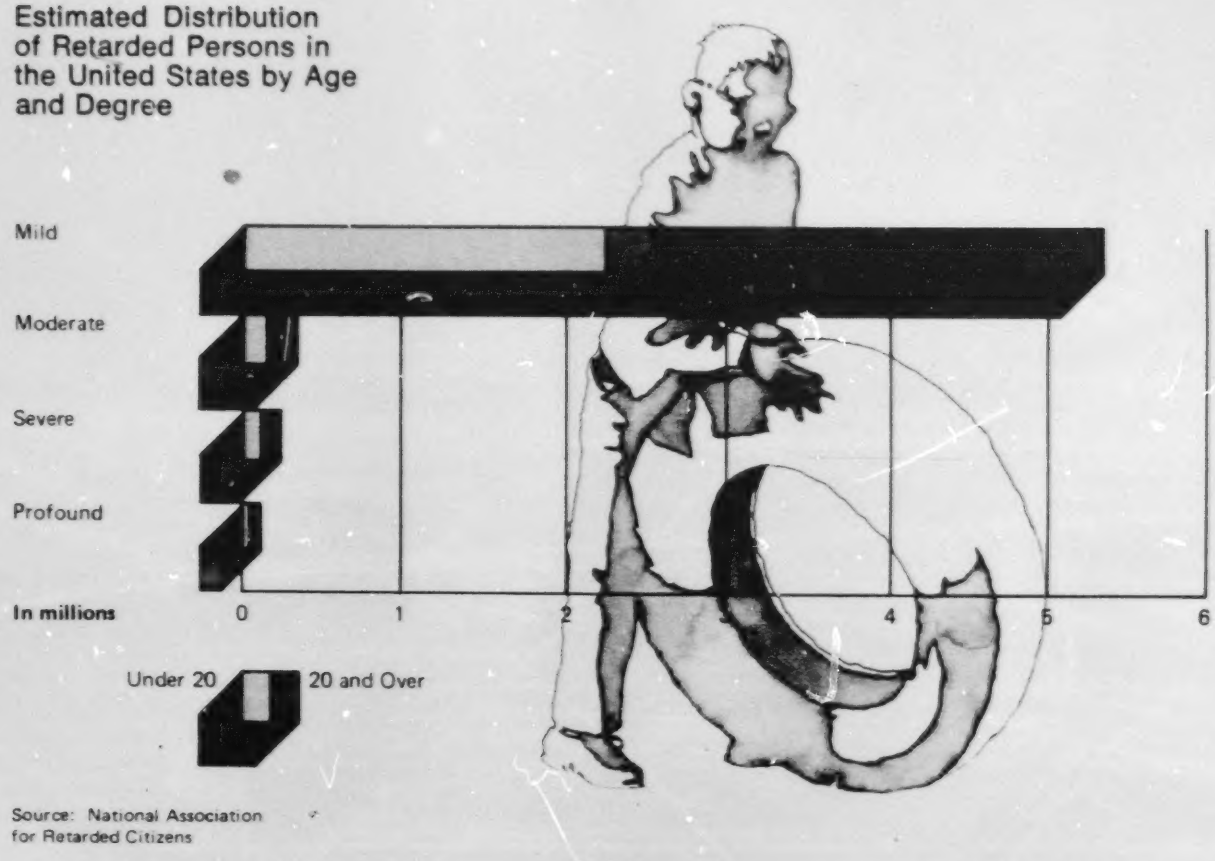
Source: Bureau of the Census.

developments in American society that would affect continued advancement toward solution of today's problems. In the present chapter we summarize the current status and the still unfinished business which mental retardation presents to us.

Mentally retarded people—who are they? In the vignettes such as that of Fritz Goebel we will see some of their faces and the faces of those who love and care for them. Broadly defined, they are people—babies, children or adults—who are substantially impaired in intelligence and in ability to cope with the complexities of everyday life.

There is no sharp dividing line between the subnormal and the normal; nor are those who are retarded equally impaired in all human functions. They differ as much among themselves in their patterns of assets and limitations as do all of us, but their overall capabilities fall short of what we expect of people of their age and experience.

Mental retardation can occur in any family from any of a great number of causes, many of them still unidentified or not well understood. Some forms occur more frequently under specific social and environmental conditions. Some forms have genetic origins and recur in particular family groups. Some are the result of birth accidents or disease. Mental disability may vary from the borderline of sufficiency to a profound degree of impairment.



Depending on where and how we draw the lines, retarded people in the United States number between four and six million. But a vastly greater number than the retarded people themselves are affected. Their immediate families embrace at least 20 million and their extended families many, many more. The number of persons involved with the problem occupationally and professionally or in the interactions of daily life is impossible to calculate. Ultimately, everyone is involved indirectly in terms of helping pay its social costs and in facing its not wholly predictable risks to every family.

The total cost of the problem of mental retardation to American society runs annually into billions of dollars and incalculable human anguish and pain.

Can this monumental problem be solved? The past 25 years have shown us much that is possible.

- Application of present knowledge of genetics and human reproduction makes it increasingly possible to minimize the birth of defective babies. Future knowledge will increase this possibility.

- Application of present knowledge of the environmental hazards to prenatal development and normal birth makes it increasingly possible to avoid the occurrence of maldevelopment and brain damage in the newborn. Future knowledge may eventually make it possible even to restore and repair injured brain tissues.

- Application of present knowledge makes it possible to give babies the kind of start in life that stimulates the growth of learning and social adaptation in spite of deprived social environments. Effective upbuilding of those environments of poverty

and deprivation could remove the hazards to development that are now believed responsible for the heaviest incidence of mental retardation.

• Application of present knowledge makes it possible to improve the level of functioning and reduce the dependency of *every* retarded person regardless of the degree of disability. Increased knowledge of learning and of adaptive development, together with the discovery and application of new supportive technologies will vastly increase the independence and social adequacy of people with limited intellectual and adaptive capacity.

• Application of present knowledge makes life in normal community situations possible for the vast majority of retarded children and adults without imposing undue hardship on their families, their neighbors or those who care for them. Resort to life in institutions is less and less necessary and will probably disappear in another 25 to 50 years.

• Application of present knowledge of training and habilitation can make it possible for the majority of retarded children to become fully integrated, economically self-sufficient adults, no longer identifiable as retarded. A high proportion of the remainder can, with appropriate support, become partially productive and socially competent.

• In short: if we applied all we now know we could reduce the incidence and social impact of mental retardation by at least half. If we continue to develop knowledge and apply it to the problem at the rate of the past 25 years, mental retardation can be brought under effective control by the end of this century!

During 1974 and 1975, the President's Committee on Mental Retardation (PCMR) has attempted to review and assess accomplishments in the field of mental retardation, to detect public attitudes, to consult people working on the firing line, and to listen to the retarded people whose lives and well-being are at stake. The overriding conclusion of the Committee is that the journey to sought-for goals is still on the upward slope of the hill, that to allow a slackening momentum at this stage would have serious consequences for the future. Ways and means must be found to remove inefficiencies and roadblocks, find the most cost-effective path on the slope, and continue forward progress. In due course, the crest may be reached and the route to the resolution of the problems of mental retardation start on the downhill run. But that time is not yet.

The sought-for goals are to prevent mental retardation from occurring and to enable people who do suffer from this condition to live the most satisfactory, socially productive lives possible. These goals break down into several parts and each part has many branching elements. The total problem is not limited to a specific part of the population so that it can be dealt with in a concentrated form. It pervades family and community life, involves a wide range of occupations and professions, community organizations, the educational system, and the agencies of government. The programs of prevention and management depend upon intricate processes of organization, cooperation and cost distribution. Many of the current issues that we face are not so much a question of knowing what ought to be done but of organizing and integrating the resources to carry out what is now known to be beneficial, and bringing them to bear on the realization of the goals.

An issue which comes increasingly into the foreground is the relationship of mental retardation and its management to other types of human disability. This involves questions of economy in the spread of resources among competing needs, and of effec-

tiveness of general versus specialized approaches to prevention and management. Also influencing decisions will be the established attitudes of parental, professional, and governmental constituencies. The former unrealistic typing of mental retardation to mental illness has now been replaced to a large degree by the statutory identification of "developmental disabilities," a term sufficiently malleable to encompass widely different combinations of disorder by slight changes in statutory language. An individual having one substantial form of disability is likely to have other concurrent problems; this creates issues in the administrative jurisdiction and treatment of the "multiply-handicapped." Finally, in terms of organization and management, the issue of "mainstreaming" versus special treatment is currently in the foreground, with the pendulum swinging strongly towards systems which extend to retarded persons the services available to the general population.

Although accurate estimates of the range and coverage of service delivery systems in mental retardation are sadly lacking, we can be certain they are far from complete. Too few of those in need are receiving the range of services required to achieve the degree of prevention that is possible, or the developmental and supportive assistance that is desirable. Part of this gap represents the necessary time span for program development. Part of it is in the immature state of the art of applying what we do know. Part of it is in limitation of resources. Part of it is in the wastefulness of inefficient organization and insufficient accountability. Part is in the tendency of agencies to guard their own special "turf." Part of it is in the lag of public knowledge and the variety of contrary public attitudes. Whatever the weight of these multiple reasons, it is evident that there is a long way yet to go in approaching the desired goals. In the following sections we shall attempt to specify these issues more sharply.

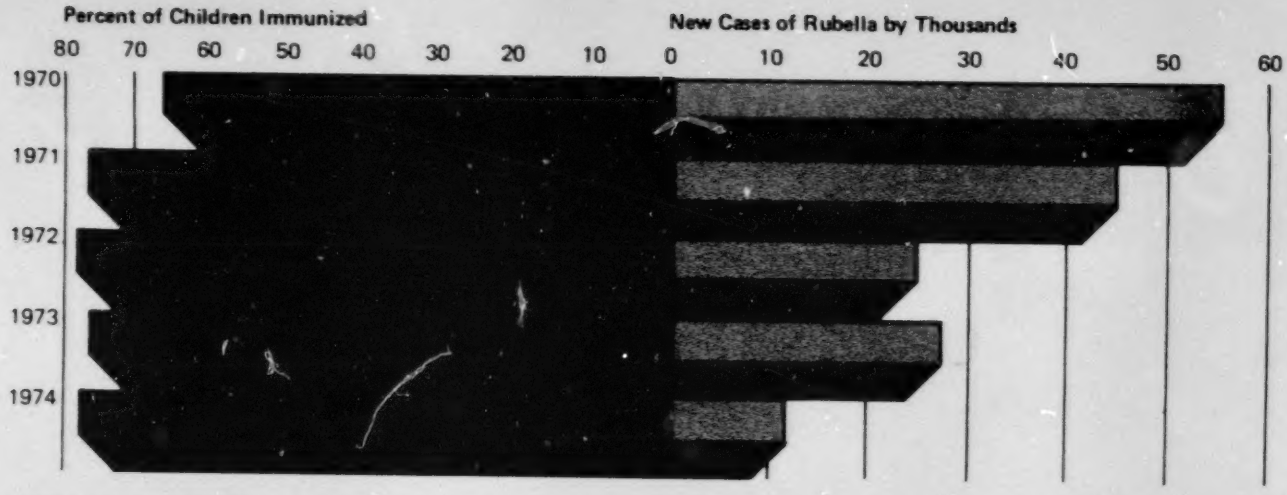
Biomedical Prevention

Modern medicine and biological science, supported by expanded programs of research, have identified several hundred specific factors which may cause damage to or maldevelopment of the central nervous system. The causes for most such defects, however, remain unknown. In a great many instances, the immediate cause of damage is the end-product of a chain of circumstances and events, the causes and conditions of which are obscure. The unraveling of these chains and networks of causation is the work of basic science and is fundamental to the development of medicine as a whole. The control of mental retardation is only one of the products of basic biomedical research, some aspects of which are more immediately relevant to the problem than others.

The biomedical problems of reducing the incidence of mental retardation center in human reproduction and the processes of early development. One essential focus of the problem is on the expansion and refinement of scientific knowledge. A second focus is on the advancement of clinical applications of knowledge to diagnosis and treatment of existing pathology. A third is on the development of public health provisions for anticipating and intervening in the causal chains that produce mental retardation. All three are indispensable elements in reducing the incidence of disability. A major contemporary issue is the integration of these three components of the health sciences by facilitating the translation of new knowledge into clinical practice and thence into public health administration.

Barriers to this flow have been of various kinds: a) the resistance of the basic scientist to working toward specific targets rather than seeking general knowledge; b) the lag of clinical medicine in picking up the products of basic science and its resistance to constraints imposed by public health administration;

New Cases of Rubella and Percent of Children Aged 5-9 Immunized



Source: U.S. Center for Disease Control.

c) the tendency of public health administration to impose rather than to develop policy and to be subject to contradictory effects of both institutional rigidity and the changes of political climate; d) the growth of university controlled medical centers which has facilitated development of new thrusts in biomedical science and its applications but tends to limit access by the full range of the population in need of service. Insofar as they exist, schisms among the three focal aspects of the biomedical attack on mental retardation must be healed if the problem is to be substantially reduced. The most indispensable requirement in health services is to maintain clear channels—from the discovery of knowledge, through the necessary technological developments, to application to the human problems that ravage our lives.

The organization and administration of health service delivery to all sectors of the population, especially to populations at risk, is an issue of broad concern. In the case of prevention and amelioration of severe forms of mental retardation it is the most crical issue. Incentive to seek service, access to it, and ability to pay for it are major ingredients in this issue.

Achievements of actual prevention of biomedical retardation have been notable in some instances and promising in others. A great deal of knowledge developed from basic research is ready for implementation and public dissemination, but is impeded by lack of field-testing and demonstration.

Among the positive achievements are those involving immunization against rubella and rubeola, the use of globulin in preventing Rh sensitization, the elimination of endemic cretinism by supplying dietary trace iodine and the reduction of congenital cretinism by thyroxin supplement; the reduction of damage in newborns from oxygen deficiency and other sources of injury; screening and dietary control of PKU and other inborn errors of metabolism; partial control of poisonous substances

such as lead and mercury, known to produce brain damage. Genetic counseling is still at a developmental stage but, aided by techniques of chromosomal analysis, screening for some types of dangerous defective genes and the use of family pedigree information, it is becoming increasingly useful in family planning. Techniques of maternal serum analysis and amniocentesis, coupled with legalized abortion, have opened the way to informed decision on continuance or termination of pregnancy in cases of detected fetal abnormality. Improved but still imperfect contraceptive techniques make possible the concentration of reproduction within the parental age ranges and conditions of family support most conducive to developing normal children.

The greatest urgency in the biomedical field is for careful planning for the balanced use of resources in providing for

- short-term payoff, through immediate health care and service delivery.

This requires expansion of maternal and child health care, and the use of presently available technology in detecting and treating abnormal conditions involving or threatening to cause mental retardation.

- intermediate payoff through preventive measures.

This requires continued universal immunizations; expansion of genetic counseling centers; control of environmental hazards such as lead, methyl mercury, and toxic radiation; contraceptive information and improvement of techniques; education in human reproduction.

- long-range payoff with maximum prevention developed from basic research.

This requires concentration of attention on genetics and cytogenetics; fetal research in all aspects of development, including the placenta; nutritional research on the nature and effects of malnutrition on the development and functioning of the central nervous system; research in the neurophysiology of growth and repair, with use of developing technologies of electrode implantation, biofeedback, etc.; cellular biochemistry and physiology especially on the functions of the membrane; brain research, including the blood-brain barrier, etc.

If, in the immediate future, there is only limited increase in health care resources, it is essential that the research sources of long term payoff not be allowed to dry up. The prevention of mental retardation depends upon a continued, even if limited, advancement on all fronts, with the short-term, intermediate-term, and long-term challenges in reasonable balance. To be effective, this means greatly improved efficiencies in management, coordination, and implementation at all levels.

Social-Psychological Prevention

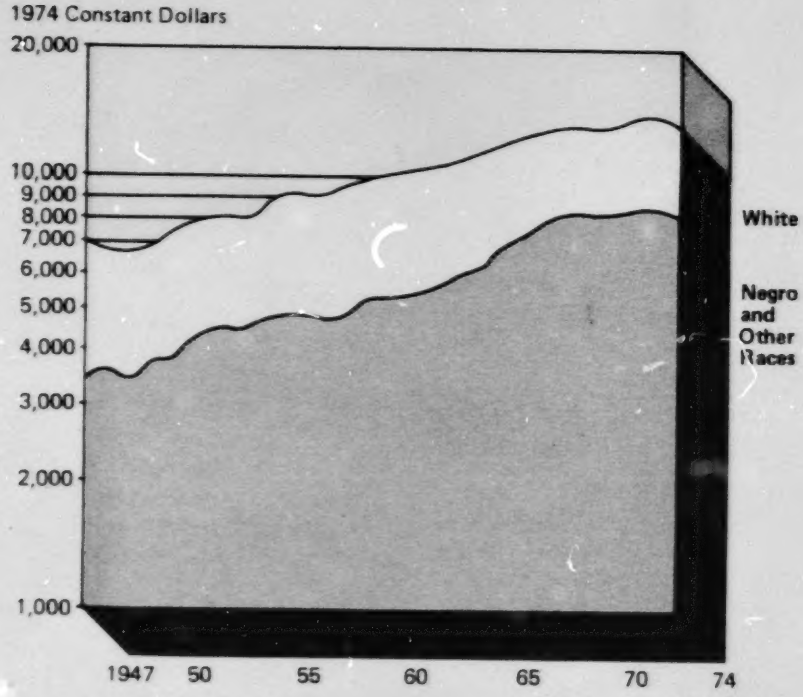
Mild retardation, occurring without detectable organic pathology, has been found to be concentrated in the most marginal socioeconomic groups, especially in the deteriorated inner cities, isolated improverished rural sections including Indian reservations, and among certain ethnic groups of low economic status.

A major issue, currently involved in litigation and legislative activity, concerns the methods by which mental retardation is identified among these groups. The evidence suggests that one reason for the high frequency with which some special populations are identified as mentally retarded in school settings is cultural bias, especially in the testing of children from non-English speaking homes with different cultural patterns. The issue of culture-sensitive methods of testing is linked with issues of educational, social, and cultural pluralism or enforced cultural uniformity.

Even with full recognition of such misidentification of children as retarded because of cultural bias, it nevertheless remains true that genuine mental retardation, usually mild, often appears in conjunction with poverty, cultural deprivation, and familial deterioration.

The controversy over the causation of "cultural-familial" retardation, as being "nature" (inherited) or "nurture"

Median Family Income, By Race of Family Head: 1947-1974



Source: Bureau of the Census.

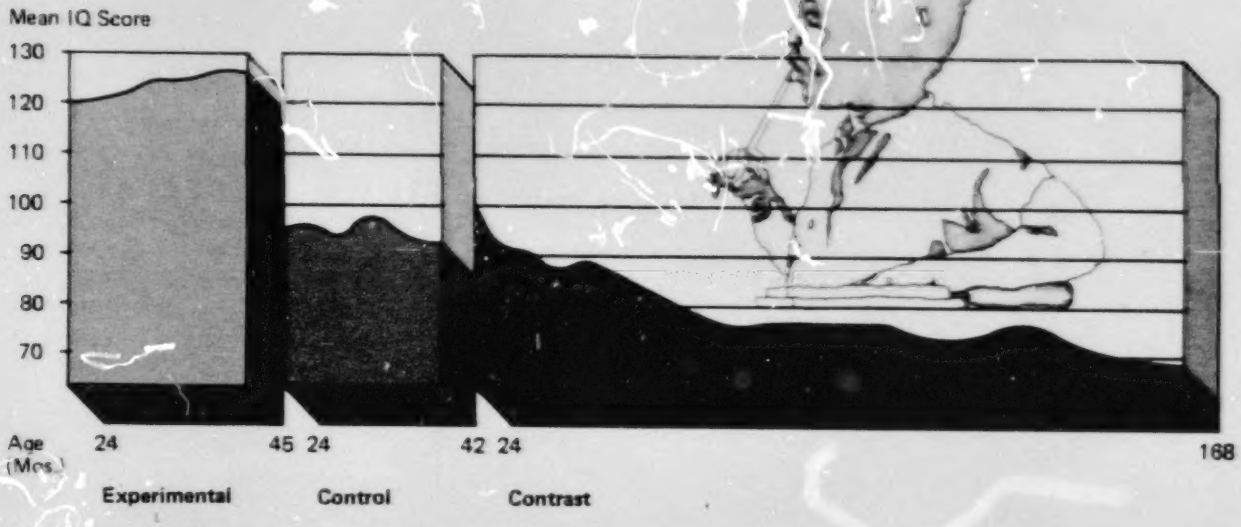
(environmental conditioning) is no longer the main issue. Enough evidence of the effects of environmental stimulation on the development and functioning of intelligence has been accumulated so that current issues of research and practice center on the learning-developmental process, the environment in which it occurs, and the techniques and timing of intervention to achieve the best outcome.

Important fundamentals of social policy underlie surface issues of definition, identification, and treatment of mild, sociocultural retardation. The more basic questions relate to ethnic discrimination and the "environment of poverty," and cover the socio-economic-political-educational waterfront. Insofar as mental retardation has been found to be related to the environment of poverty and its ethnic and racial aspects, the long-range prevention of retardation from this source may well depend on the long-range resolution of these underlying sociological issues.

Poverty creates an environment which has devastating effects on human health and development. Mental retardation from virtually all identifiable causes has a higher incidence in impoverished and socially deteriorated environments than in any other. This is the result of malnutrition, poor medical care, cultural deprivation, health hazards of living conditions and housing, disrupted family life, and the psychological factors of hopelessness, apathy, and despair.

In the short range, techniques of early intervention involving children most at risk from sociofamilial causes have shown promise, especially in those cases involving low intellectual functioning of mothers in deteriorated cultural and economic environments. Knowledge is insufficient as yet to provide the range of techniques and programs required for general application to varieties of settings. Continued longitudinal research on fundamental developmental and learning processes, and field-testing the findings for general use, is badly needed.

Experimental, Control, and Contrast Group IQ Scores (Mean IQ Score)



Source: Rick Heber, Ph.D., and Howard Garber, Ph.D., University of Wisconsin, Madison.

Critical policy issues in prevention of social-psychological retardation arise when we attempt to define mild and borderline deficits. A mentally retarded person invariably presents a profile of both assets and deficits, which range in varying degrees from the norm. These variations frequently are lost sight of when they are arbitrarily summed up in an I.Q. This becomes a particularly dubious practice when regulations on eligibility for special classification or treatment reflect the fixed dividing line. One example was seen when the American Association on Mental Deficiency changed its definition of mental retardation in a way that eliminated those on the "borderline" level. This resulted in making them ineligible for needed vocational rehabilitation services. An attempt was made to repair the damage by a later modifying statement which recognizes exceptional cases. The definition of "developmental disability" in P.L. 91-517 (Sect. 140) and repeated in P.L. 94–103 (Sect. 102) deliberately went even farther and focused explicitly on the more seriously impaired who were more obviously underserved. By including in the phraseology "[disability] which can be expected to continue indefinitely," the statute virtually excluded mildly retarded persons from its application inasmuch as they are expected to benefit from developmental training and assistance to the point where they can make an adequate personal and social adaptation to adult life—hence cease to be retarded. Yet to achieve such a "disappearance" with hope of more than marginal subsistence may depend precisely on the availability of those services for which Developmental Disability programs are designed to promote support. Although it is true that the mildly retarded were more likely to receive attention in earlier special education and vocational rehabilitation programs, there is some danger that this group, constituting nearly 90 percent of the population identified as retarded in the developmental years, may become the neglected ones.

Mildly retarded children in the school system have the best prognosis for adult adjustment and "disappearance," but to label them as "retarded" may, in fact, be damaging and reduce the prognosis of full social integration. Yet not to recognize and treat their cognitive and adaptive needs may also prevent effective development.

The alternative approach to the problem, that of starting with the individual child and prescribing programs tailored to that child's needs, may present problems of administration, but at least does not exclude children from needed services by an arbitrary definition.

As an issue relating to the goal of reduction in incidence of mental retardation, we can hardly be content with a procedure that achieves reduction merely by definition or declassification. Developmental deficits emerge from sources embedded in the social milieu in which children make their start in life. It is the reduction of such deficits in whatever degree possible that is of greatest concern.

In summary, the issues of prevention of mental retardation from "cultural familial" or "socio-psychological" causes are these:

- Short-range improvement in methods of identifying the true nature of apparent retardation, not to exclude the misclassified from needed services, but to provide the services appropriate to the real problems. This achieves reduction by appropriate diagnosis and prescriptive treatment.

- Short and intermediate-range diminution or avoidance of deficit by early interventions in the developmental process, with follow-along as needed into adult years to reach, it is hoped, an eventual status of independence in an adequately adapted mode of life.

- Long-range basic research on the psycho-social developmental process to obtain new knowledge applicable to intervention and supportive strategies.

- Long-range approach to the elimination of the "environment of poverty" as the root source of socio-psychological mental retardation. This approach must be a comprehensive one in terms of social, economic and cultural contributors to the total problem, including racism. It addresses itself to improvement in the total quality of life for the disadvantaged segments of society.

The Retarded Person as Citizen

The status and role of the retarded person in society are determined by the complex interaction of many factors. Among them are:

- The prevailing "image" or stereotype of mental retardation in terms of which the retarded individual tends to be perceived. This may itself be complex, with "image-layers" derived from historical sources in the cultural background. Such image layers are in varying degrees conscious and subconscious and interact with other elements in the ongoing psychosocial processes of individual and group behavior. Thus, a neighborhood may react warmly to an appealing child with Down's syndrome, perceiving a "child of misfortune" who deserves a charitable nurturance; but that same neighborhood may resist the establishment of a group home for young retarded adults, perceiving threats to personal safety from hidden "demonic" qualities, including unconstrained sexuality and irrational aggressiveness presumed to be characteristic of the mentally deficient. This attitude is usually augmented by supposed threat to property values.

A volume being developed for later publication traces the history of the deeply derogatory image of the "feeble-minded" which flourished in the late 19th and early 20th centuries. This negative image was preceded by a somewhat vague but more tol-

erant attitude toward deviance deriving from democratic and egalitarian movements of the 17th and 18th centuries. In turn, the 20th century has witnessed the emergence of the innocent child victim deserving a nurturant charity, followed most recently by the concept of the retarded person as citizen. Thus our inherited culture may contain at least four "images" of the mentally impaired person, superimposed and not fully reconciled with one another, but all affecting the response we make to the retarded person in our midst.

It is important to realize that the "citizen" image of the retarded person is still a very thin layer in the consciousness of the community. In many ways it is difficult for people to assimilate because it contradicts the established identification of citizenship with responsible competency: the mentally deficient individual, whether accepted or rejected, is generally seen in terms of incompetencies and lack of responsibility. This has been bolstered by law and custom. Hence, the intense public information campaigns that have been conducted in the past 10 years by public and private agencies have had to buck ingrained habits of thought and feeling which make the notion of retarded "citizen" somewhat incredible. It took the National Association for Retarded *Children* eight years of discussion to convert its avowed recognition of the retarded person as a member of the citizen community into a change of name to the National Association for Retarded *Citizens!*

The current status of retarded people is, therefore, profoundly influenced by the persistence of multiple layers of perception and attitude. The deeply derogatory stereotype of 60 to 80 years ago has been broken, but a clear image of the retarded person as a community-participant has not yet stabilized.

• The established patterns by which society has made an investment in a system of management. The 19th and early 20th century organized a pattern of management of the mentally retarded based preponderantly on exclusion and control, with the normal arrangements for meeting the needs of children and adults in the community designed in ways inherently *un*accommodating to the mentally retarded. Thus, housing required contractual and other responsible behaviors tending to be limited in retarded persons; employment was normally possible only if an individual could produce at a competitive level; schooling was modeled on a pattern of abstract conceptualization, striking at the most salient weakness of the retarded child.

Arrangements made to accommodate the mentally deficient, *outside* of the standard system, involved extremely durable buildings on costly land with built-in systems for perpetuating dependency and incompetence. The alternative was for the family to maintain the deviant person in the hidden recesses of the home, at great financial sacrifice. Schooling, when it developed, was a parallel system of "special education," which, fortunately, had sufficient flexibility so that its inherently denormalizing features did not irreversibly take over the field. Employment of the retarded, when it occurred, was first made an instrument of servitude to support the segregated residential institution; then, when external employment was initiated it became a stepchild of vocational rehabilitation, which was firmly established as a means of providing rapid retraining of previously employed people who had suffered physical disability. Hence, the sheltered workshop had to function largely as a separate productive system with only tenuous attachments to open productive industry. Most of the retarded persons who made successful entry into open employment did so by ceasing to behave in ways that suggested mental deficiency, usually without the assistance of anyone. They tended to remain, however, as the lowest-paid unskilled workers, most vulnerable to layoffs.

Currently, the breaking through of established organizational rigidities has proceeded part way, but strong resistance to change is still present. Residential patterns are changing, at least superficially, but this may be in part an accommodation to pressure of advocate groups, not a fundamental shift of social investment. Some general public services are beginning to include persons with varying degrees of retardation, but development is uneven and sometimes superficial: school systems are struggling with the process of "mainstreaming," communities are struggling with accommodation of group homes and other forms of living arrangement for retarded persons, employment agencies and rehabilitation services are slowly finding ways to include the adult with limited capacities for productive work. The major professions, accustomed to the "normal" needs of their constituencies, have had to learn the necessary accommodation to those who vary from the norm. Professionals of all types still are divided among those who are indifferent, hostile or unaccommodating to retarded people, those who accommodate as part of normal practice, and those who have become active and devoted advocates of the mentally retarded client. Organizational and ideological rigidity remains a potent factor in all segments of society in determining the status and role of the retarded person.

• The legal system, including statutory law, quasi-legal practices, and the operation of the courts. Local ordinances, which once regulated the public policy regarding markedly deviant persons, including the mentally defective, were increasingly superseded by State laws in the early 19th century. These statutes, varying greatly from State to State, were a mixture of generally applicable regulations regarding competency, guardianship, public welfare and the like, and special laws regulating mentally deficient persons. In general these statutes tended to be restrictive and exclusionary, designed primarily for the protection of general community in-

terests and only secondarily for the protection of the retarded person. The laws were full of inconsistencies (e.g., establishing equal right to public education of all children, but elsewhere excluding the "feebleminded"), vague language and violations of fundamental constitutional rights. Many statutory provisions were unrealistic, inappropriate and unworkable, hence were inconsistently applied or ignored (e.g., laws restricting marriage by retarded persons, laws requiring teachers to report to legal authority all children suspected of being "feebleminded").

The landmark National Conference on the Mentally Retarded Citizen and the Law sponsored by PCMR in 1973* was a natural consequence of issues raised by the emergence of the concept of the retarded person as a citizen. If the individual person who happens to be retarded is a citizen in a legal as well as in a euphemistic or moral sense, then what in fact is his status under the law? The conference found, as had other investigations, that the status was ambiguous, frequently in violation of Federal constitutional guarantees of due process and equal protection of the laws, and in large measure in contradiction to developing concepts of sound public policy in regard to mental retardation and the treatment of the mentally retarded person.

In the years prior to the conference, there had been developing a strong movement to define and to protect the rights of mentally retarded persons. Most notable of these efforts was the Declaration of General and Special Rights of the Mentally Handicapped, adopted by the International League of Societies for the Mentally Handicapped in 1968, endorsed by organizations and governmental bodies in many countries, and finally adopted, in somewhat modified form, by the General Assembly of the United Nations in 1972.

The chief import of all such declarations of rights was that the mentally retarded person has all the fundamental rights of any other person of his age and nationality; that such rights may be limited or abrogated only by lawful juridical process, and that the exercise of rights must be protected by positive assistance in the presence of handicapping conditions. Lists of specific rights to which the retarded person is entitled generally center on the following:

- The right to due process and equal protection of the laws.
- The right to live in the least restrictive and most constructive circumstances the person's condition will allow.
- The right to exercise free choice either directly or through a recognized representative or guardian, and to undergo the risks inherent in freedom of choice.
- The right to guardianship or other form of protective advocacy.
- The right to education and training appropriate to developmental status.
- The right to freedom from discriminatory restriction solely on the basis of mental retardation.
- The right to fair treatment in the courts when accused of unlawful conduct.
- The right to freedom from cruel and dehumanizing treatment.
- The right to vote.
- The right to marry and to procreate.

The issues surrounding the protection and advancement of the rights of the retarded have been developed within the gen-

* A popular representation of the findings of this conference was published by PCMR under the title *Silent Minority* in 1974, and is available from the U.S. Government Printing Office for $1.00. The complete set of professional and scholarly papers is being published by The Free Press division of Macmillan.

eral civil rights movement of the mid-20th century. The retarded have not marched in the streets or resorted to civil disorders; they themselves have only on rare occasions been directly articulate in expression of their rights. Their advocates and representatives, however, have sought redress of their grievances in the halls of Congress and in the State legislatures, before county commissioners and city councils. In the past five years they have appealed to the courts in a long series of individual and class action suits. These suits, now numbering well over a hundred, have yielded a number of landmark decisions which are having profound effect on the revision of Federal and State laws, on administrative regulation and on subsequent action of the courts themselves.

Simultaneously, actions brought in behalf of other groups of handicapped persons (e.g., those who are mentally ill, epileptic, physically impaired) have been of concern to the advocates of mentally retarded persons, since similar principles of right may be involved. In a number of instances, they have entered these cases in the role of *amicus curiae*.

Although the basis of suit has ranged from local ordinance to the Federal Constitution, the principal appeal has been to the constitutional guarantees of equal protection of the laws, due process of law, freedom from cruel and unusual punishment, and freedom from involuntary servitude. The suits have claimed the right to educational placement and treatment; the right to community services including adequate medical services and to treatment in the least restrictive setting; the right to due process in commitment procedures; the right of freedom from involuntary servitude; the right to freedom from restrictive zoning ordinances and from barriers to public buildings and transportation systems; the right to marry and to procreate.

All of these represent real issues of citizenship, taken as a matter of last resort to the courts. Many similar issues are being promoted through channels of discussion and arbitration, legislative advocacy and administrative regulation.

Central to the whole process is the issue of the competency of the retarded person to speak and act on his own behalf, to freely engage others to act as his representative, or to have a representative appropriately appointed in case he is unable to exercise such choice. Who speaks for the retarded, individually and collectively, remains a matter of central concern. It involves the question of freedom from the established biases of government or service delivery agencies. It involves the question whether parents are or should be a natural representative in all cases. The vexing issue of immigration of retarded persons as members of family groups has never been satisfactorily resolved.

An offshoot of the landmark cases involving general treatment institutions has been a movement among the institutions to establish codes governing the rights of residents.

The retarded person in the criminal justice system is the focus of another set of issues. These include questions of procedure in arrest, arraignment, trial and treatment. There is ample evidence of limited sensitivity of the courts and of law enforcement personnel to these issues. Hundreds of retarded persons are in jails or prisons without full understanding of why they are there. Procedures relating to degrees of responsibility and to the clear presentation of all relevant facts pertaining both to the person and to his alleged acts are in need of clarification.

Closely related to the issues of legal and civil right are the issues of moral and ethical right. Society legislates for what it regards as minimum morality, or the protection of human values on which there is general agreement. Other matters of morality and value decision it leaves to individual conscience and decision. The question of the extent to which regulation should be by law or conscience is always difficult and tends of fluctuate, and borderline issues become matters of highly charged controversy. On what basis, for example, is suicide a crime? Or at what

point should pornography come under legal control?

In the field of mental retardation there are a number of such controversial isues that lie between morality and law. The treatment of profoundly abnormal babies is a case in point. To what extent are life-saving or life-prolonging procedures to be used? Who has the right or the obligation to make decisions in this matter? The law may determine that the right of choice must be protected—but whose choice? If procedures are permitted with "informed consent" whose consent is required on what issues? How far does a parent have the right to choose or consent for the child? Is the choice expressed by a retarded person to prevail over parental or over professional judgment?

The citizen status of mentally retarded people may be affirmed in principle, even established by law in certain respects, but still be a long way from actuality in practice. The mentally retarded are not unique in this regard; the distinction between status *de jure* and status *de facto* is familiar in everyday life.

This means that there are always practical issues to be met and dealt with on the firing line, where life goes on. So, for retarded people, the full attainment of the status and role of citizens is a never-ending process, in which victories in court or in the legislature may still be followed by defeat in the community. Part of the problem is, of course, that the issues are never purely legal. The interactions of everyday life, in which people act on their beliefs, perceptions, their self-interests and their concern for others, will always, in the end, make the difference. For this reason, the issues surrounding the spread of information, the improvement of public attitudes, the changing of negative perceptions into positive ones, become paramount. Until the retarded person's neighbors and associates and employers and the others with whom he interacts see him in the role of citizen-member of the community, he will not really be one.

Humane Services

We have come to look upon the mentally retarded person as a human being whose developmental stage differs to a noticeable degree from that of the usual person—the difference involving a deficit, a lag, a retardation behind the norm. This lag is, to a degree, quantifiable, so we can speak of degrees of retardation and classify retarded persons accordingly. This is useful for some purposes, but if taken too seriously it results in freezing the retarded person in a fixed category. That was the general practice during the first half of this century and still persists to a considerable degree. It has the effect of generating static treatment concepts based on fixed predictions of attainable performance levels. Today, the prevailing view is based on different premises constituting what is called the "developmental" model.

- The development model of retardation assumes that the individual is a changing, developing person within whatever limits are imposed by his constitutional or acquired characteristics.
- Every individual, no matter how severely impaired, is capable of learning so long as life endures and the person is in any way responsive to the environment.
- Changes may be fostered in desirable directions—i.e., toward the maximum development of human qualities—by processes of education and socialization as well as by nutrition and physical care.
- The provision of services for mentally retarded persons therefore has the same goals as the services for all children and adults, and requires recognition of and adaptation to the uniqueness of the individual and his needs.

The issues surrounding the provision of services on a humane developmental model are both general and specific. Among the general issues are those relating to (1) the elimination of practices contrary to developmental goals, (2) the use of generic service systems versus separate provision of services, (3) organization and administration of services delivery, including eligibility and access, and

(4) public responsibility, fiscal support and accountability.

• As we have seen, the prevailing policies of the past generation or two have been directed to goals other than the maximum development of the retarded individual. Those goals became firmly fixed in practices and agencies which formed part of the established social structure. Although many changes have taken place, there are still massive residuals of outmoded practices. These are represented in statutes, in governmental organization, in the policies and operation of agencies as well as in the forms of service provided by schools, residential institutions and commercial enterprises. A major issue of humane service delivery is in the turnaround of these outmoded practices and their redirection to developmental and humane goals. Such turn-around is difficult because of massive rigidities in the way organizations think and operate, established vested interests, and deeply rooted habits of individual perception and conduct.

• Generic service systems have been traditionally designed to provide for what is regarded as a "normal range" of human differences. Individuals whose characteristics vary beyond such a range find it difficult or impossible to use the services profitably. Most service systems tend to become standardized and to pay little attention to the unique needs of individuals; they assume that individuals will accommodate to the "system" rather than the reverse. One issue which has become widely current is that of making social systems more generally responsive to the individual. For the mentally retarded the issue goes beyond that to the question of the limits of adaptability of generic services to the more extreme differences in individuals. This resolves itself into the consideration of wide ranges of circumstances, e.g., in health care, education, residence, recreation, work settings, etc. The general issue, however, revolves around the objectives of maximum flexibility and adaptability to meeting special needs within the standard system, resorting to special or separate systems only when the limits of feasible "mainstreaming" are reached. Not everyone will agree where those limits are.

• Individuals, retarded or not, are whole beings with interlocking and interdependent needs. Human services tend to be dispersed and fragmented, requiring the individual to find his way from setting to setting as best he may. This is difficult enough for the person with high levels of intelligence and adaptability, but becomes increasingly difficult for those whose functions may be impaired. Consequently, the issues represented in the concepts of "continuum of care" and "fixed point of referral" formulated by the President's Panel in 1962, and the concepts of "follow through" and "follow along" that have appeared in subsequent literature, represent a continuing vital issue. The existence of an unmet need should be the basis of eligibility for service. Too often, different agencies impose different definitions of eligibility, which cause the retarded person to fall between the cracks. The organization of service delivery systems to provide ready access becomes increasingly important as disability is the more severe and complex. For example, a mildly retarded young adult may learn to move relatively freely from residence to work to social activity center to counseling center to grocery store and among all the settings in which he finds satisfaction of his needs and interests. Effective education and training can aid in achieving this mobility. For the less capable and the multiply disabled person with many more specialized needs, access to service satisfaction is more difficult, the problem is more complicated. Being less independent, the person requires not only more services but a more highly responsive system which can keep the multiplicity of his needs in common focus.

• The issues of public versus private responsibility, financial resources and locus of accountability reach into the arena of political philosophy and controversy. In the last half-century the United States—and the modern world generally—has moved steadily in the direction of public responsibility for a wide range of fundamental human services. The consequent growth and complexity of governmental

organization creates problems of inefficiency and lack of accountability as well as of depersonalization, which can become counterproductive to the goals sought. Yet there appear to be real limits to the ability of private effort to provide the range and types of services required and expected by the citizenry. The issue of feasible and appropriate division of public and private responsibility, the organization and distribution of functions and the articulation of systems of information, evaluation, planning, execution and quality control is a massive one.

The special issues of human service delivery to the mentally retarded have chiefly to do with the composition of service elements and the specific procedures by which they are made available. The recently published *Standards for Community Agencies* and *Standards for Residential Facilities* of the Accreditation Council for Facilities for the Mentally Retarded, a division of the Joint Council for Accreditation of Hospitals, develop many of the major concepts which articulate these special issues. They relate to the responsiveness, availability, accessibility, and individualization of service facilities; the process of service entry, evaluation, individual program planning; the problems of community relations, records, administration, and all the details that accompany any such operation. Central to the concept of evaluation and accountability is the emphasis on what happens to the person served rather than on service apparatus and organization. The special issue of measuring the effects of service delivery on the individual in need is the key to the entire process.

Focal issues on which attention is currently centered are the locus of service, the content of service components, and the organization of services.

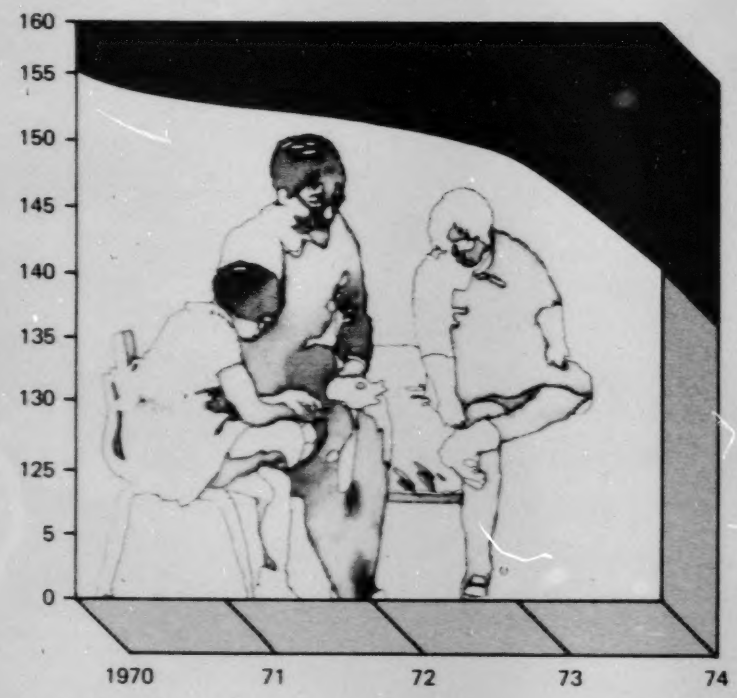
The Locus of Service Delivery

The natural and by far the most common place for retarded citizens to live is in proximity to their own families in the general community. The most natural locus for service delivery to these citizens is, then, the same as for all citizens: in the population centers where they live.

During the last century and a half, and lasting until just a few years ago, we have seen the growth of a movement to shunt the retarded person from residence in central institutions largely detached from centers of population. The purpose of this removal was not so much to provide service to the retarded person as to protect the community from the real burdens and the presumed dangers of his presence therein. Since the central institution was the focus of public provision for retarded persons, apart from some attempts to provide local special education, virtually no specialized services were made available to retarded persons in the general community, and the generic service systems of the community were not generally willing or prepared to meet their needs. The great majority, therefore, went unserved if they remained in their own homes, and received little more than custodial care if they were placed in the institution.

For the institutions to provide the range and quality of service required by the diverse characteristics of retarded persons would be extraordinarily costly. To be cost-effective in any degree, massive numbers must be institutionalized to achieve economies of scale, and the most economic pattern of service must be maintained. Historically, this resulted in a high degree of institutional regimentation (the institutional conditioning of behavior into rigid patterns of dependency), the use of resident labor to cut the costs of operation, the employment of the cheapest available professional and unskilled staff, and the reduction of service delivery to the absolute minimum in quantity, diversity and quality. The consequences of this historic trend are notorious and have been detailed in exposes and court hearings.

Population of 176 Public Residential Facilities: Fiscal Years 1970-74



Source: National Association of Superintendents of Public Residential Facilities.

Private institutions providing a better quality of care and service have been available only to families of wealth who could afford the scale of fees.

Because public service provision for the mentally retarded was concentrated in the central custodial institution, and virtually nothing was available in local communities, families, courts and welfare agencies utilized the institutions increasingly into the 1960's. These massive overcrowded, dehumanizing repositories housed a quarter of a million disabled human beings before a downward trend started around 1969. Since the advancement of knowledge made it clear that the primary objective of service should be to increase the ability of the retarded citizen to live within the scope of normal community life, rather than to protect the community from illusory dangers to the public safety, the traditional institution has become an anachronism and, in many cases, a public scandal.

The present thrust of public policy is now and must continue to be toward the development of an adequate continuum of services to meet the developmental needs of mentally retarded children and adults *within* the communities in which they can maintain their natural homes. This thrust takes three forms:

- The location of service agencies in centers of population accessible to people who live there.
- The development of combinations of mobile service agencies, 5-day boarding homes and other alternatives in the rural and sparsely populated areas of the country.
- The movement of present institutional populations into more appropriate residences within the community where services are accessible and social habilitation possible.

This is the meaning of the currently used term "deinstitutionalization." It is not simply an emptying out of the institutional population. It is a total reorientation of society to the care and treatment of mentally retarded persons. The issues surrounding this transition are massive and manifold, but they constitute the principal challenge of the next quarter-century.

The Components of a Continuum of Services

The essence of "deinstitutionalization" is the development of accessible services in the community. The question of what services, in what order of priority, is a vexing issue because the

range of service needs is so great. The following compendium is only one possible way of viewing the array of desirable service functions. The question whether the comprehensive list constitutes a "minimum constellation" of required services or an optimum complement is itself an issue on which opinions are varied. There is no question of the necessity of developing significant components of such services in each of the three principal service areas indicated below. In many instances they represent the extension to the special needs of mentally retarded persons of services taken for granted and readily available to citizens generally.

• *Protective Service*

Retarded individuals need protective services in differing degrees. A balance must be struck between underprotection which exposes him to danger and overprotection which impedes development.

•• Legal guardianship and conservatorship.
According to need, the court may appoint a guardian to represent the interests of the person, or of his property, or of both, with respect to all transferable rights. Current laws are frequently obscure and inconsistent.

•• Personal representation or advocacy.
An individual chosen by or for the retarded person to guide, counsel, and intercede in his behalf.

This is a service of great urgency. Citizen advocacy systems have been developed in some localities. A variety of such services is possible, including the development of a new function of service broker. Issues of training, qualification and certification, access, source of costs, all require careful consideration.

•• Equal protection and due process of law.
The law provides the same protection of constitutional and statutory rights for those who are retarded as for all other citizens.

•• Employment safeguards.
Protection against exploitation but also protection of the right to work under fair labor practices according to ability and to equal compensation according to production.

•• Income maintenance above poverty level.
Inability to earn a full living does not justify a marginal or submarginal standard of living.

Income maintenance is a general public issue which will continue to be hotly debated in terms of various alternative systems. Our concern is that people of low productivity not be penalized by the work-incentives built into present systems of security income, thereby restricting the less productive individual to the extreme poverty level of subsistence.

•• Insurance coverage.
Economic protection against hazards to health and to possessions for the retarded person and his guardian.

A related issue is that of an insurance system protecting prospective parents against the costs of severe disability in a child.

•• Protection against abuse, neglect, or being lost or abandoned.

• *Developmental Services*

Adequate services in this category are those necessary to maximum utilization of the individual's capacities for growth.

•• Pre- and post-natal maternal and child care including early developmental assessment.
This requires special attention to the principle of accessibility, particularly in remote rural and congested urban areas.

•• General and special health services, including preventive and restorative dental care, needed surgical corrections, technical and mechanical prosthetics and health maintenance.
Persons with retardation at any level of severity are likely to be more than normally vulnerable to health hazards, from either

physical or social causes. Health maintenance, including adequate nutrition, and reduction of secondary impairments, can prevent multiple handicapping and promote positive development.

•• Early childhood developmental assistance.
This includes both physical and social forms of guided stimulation, especially important for infants and young children judged to be at risk. Early treatment may have either preventive or ameliorative effects relating to mental retardation.

Early intervention in all appropriate forms appears to be one of the most promising means of minimizing the risks of potential or actual retardation.

•• Legal assistance and services.
In addition to basic legal protections, positive services should be available to families facing the problem of retardation and to retarded persons themselves, on a basis of need.

•• Education and training in all aspects of self-care, personal management and cognitive skills.
The United States is moving swiftly to a "zero-reject" system of public education. This requires the development of new, versatile and adapted environments for learning geared to individual need and capability.

The two sharpest issues in the educational field currently concern, (a) the inclusion of retarded children in school settings with non-retarded children, and (b) methods of stimulating learning in the severely and profoundly disabled. The latter requires development and refinement of techniques beyond those

of current behavior modification, and the development of personnel with adequate training and skill.

•• Social developmental stimulation, recreational and physical development.
Services must frequently counteract the social isolation and recreational immobility of individuals with retarded development. This applies at all ages, and involves development of physical fitness, motor skills and controls, and general physical proficiency to the limit of possibility.

•• Spiritual nurturance and cultural training.
Retarded children and adults have the same needs as others for experience in the realm of spiritual, moral, and aesthetic values. Within the environment of their own culture, they can develop sensibilities to and expressions of these values.

Many religious denominations are developing programs of instruction and inspiration to include retarded children and adults. Programs in the arts, including music, dance, graphic arts, ceramics and other forms, are not only appropriate but necessary to a full life for retarded people.

•• Vocational training.
The retarded individual can approach normalcy as an adult only if productive and occupational skills are developed. This must be adapted to individual assets, not based on measured deficits.

Vocational training requires thorough rethinking in terms of the whole range of productivity levels and in terms of the kinds of work opportunity that will be most available to retarded people in the future. A special issue in the case of mildly retarded individuals is the effect of labeling on employability.

•• Compensatory and continuing education.
There is no age or developmental point at which beneficial learning begins or terminates. For retarded individuals, especially those whose learning has been neglected in the so-called "school-age" years, there should be continued open opportunity for learning under appropriate conditions.

The essential issue is really a generic one: whether public education should be open-ended with regard to both ends of the age scale, permitting early stimulation as well as continuing guided learning. The latter may well be geared to shifting occupation.

•• Evaluation and counseling services to accompany all developmental phases.
The purpose of evaluation is not primarily to classify but to assist. Associated with counseling, it explores and utilizes developmental assets to reduce and compensate for developmental deficits, seeking the best combination of service supports to achieve this end. Counseling helps the retarded person make his own choices and define his purposes and life goals.

• *Supportive Services*

Assuming the individual who is retarded has developed capabilities that are useful but insufficient for independent living, what services are needed to supplement and utilize his capabilities?

•• Family services.
These may be of many kinds, to support either the family responsible for the management and nurturance of a retarded child, or the adult retarded person himself in his efforts at self-maintenance.

•• Residential living options.
Individual need and choice, both in childhood and as an adult, require a range of options for residence, in terms of level of care offered, type of setting, familial quality, group size, supplemental services, general conditions. The objective is to provide these options within the boundaries of the "community" on a local or contiguous regional basis.

This is the core of one of the prime issues: the nature and timing of the reduction and change in role of the traditional services of residential institutions. Knowing that their child will have a safe place to live even after they are gone is the primary concern of parents.

•• Employment and meaningful daily activity.
Productive, constructive activity,

as economically valuable as possible, is an integral part of normal life. Gradations from simple socialization to full employment in the open market are needed, with the appropriate degree and type of supporting service.

•• Mobility and transportation. The objective here is to enlarge the scope of the world for the retarded person. Supporting services may range from physical prosthesis, to guides to the "mapping" of the environment, to personal vehicles, to public transportation systems, and may include aids to acquiring a driver's license.

The possibility of new technological aids to environmental mobility of the mentally retarded opens new channels for research and demonstration projects.

•• Social life and recreation. The greatest problem in the life of a retarded person is loneliness and boredom. Supportive service is directed at the prevention of social isolation and access to physical, recreational, and socially enriching contact which is satisfying to the person and his associates.

•• Supports for marriage and family life.

The same principle that recognizes degrees of supported and protected productivity and employment can apply to marriage and family life. Basic to service in this area is counseling which reflects the individual's wants, needs, and capabilities. Family life can take many forms, with many possible combinations, only some of which involve marriage, only some of which involve having and rearing children.

It is necessary in this area to separate issues which are often confused because the functions frequently go together: sexuality and its management, marriage and other forms of affectional companionship, child-bearing and child-rearing. Each is a separate issue, but the conjunctions are also controversial.

•• Old age services. Increasing longevity characterizes those who are retarded as well as those who are not. Aging brings changed needs and changed desires. Aging in the end brings all people to common terms of need. The objective here is to provide for the decline of life functions on a basis of respect for the dignity of the person.

Political and Economic Issues

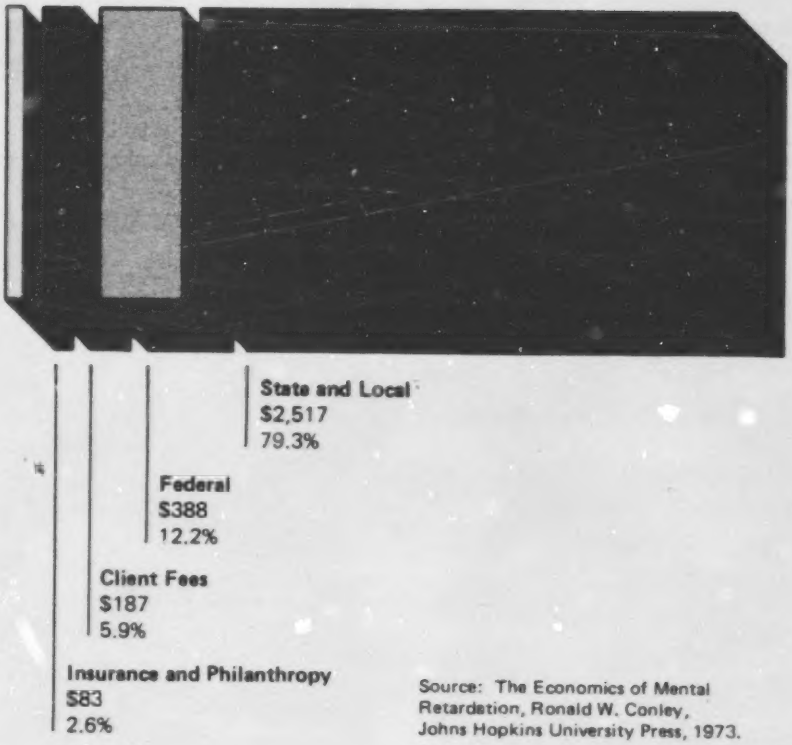
Administrative and fiscal responsibility for the problem of mental retardation, its prevention and alleviation, is currently divided between public and private agencies, and further distributed among levels of government and types of private social institutions. There are issues at all points with respect to the nature and equity of the distribution, with a good deal of uncertainty as to the direction matters will take. The situation is extremely fluid, but is beginning to stabilize at some points.

The Federal Government has taken a leading role in the past 20 years in providing resources directly and through the States to advance solutions to the problem. The States, on their part, have made substantial progress in the planning and development of services and the provision of increasing funds for their support. Local communities, usually at county level, have been the scene of increasing activity in service delivery as programs of deinstitutionalization and normal developmental opportunities for mentally retarded citizens have moved forward. Fiscally, the heaviest burden has been borne by the States, but the Federal contribution has mounted to a substantial annual sum when support of services and income maintenance are combined.

On the private side, the most prominent contributor is the family which, traditionally, has felt the greatest share of the burden in terms of social, emotional, and relative financial costs. Indeed, it has been the inability of families to sustain this burden that has been the prime mover of governmental intervention. Other shares of private responsibility have been assumed, however, by service clubs, privately organized or church-related charitable and welfare groups, the associations for retarded citizens and the millions of people who contribute volunteer time, effort and funds to their operations. Among private foundations, the Joseph P. Kennedy, Jr. Foundation has steadily and imaginatively contributed substantial funds in support of research and service development. The Jaycees and Civitan Clubs have had special service projects. Members of the professions, lawyers, teachers, physicians, dentists, clergy, social workers, psychologists, nurses, speech pathologists and audiologists, physical and occupational therapists, recreation specialists, guidance and vocational counselors, and many others have become increasingly involved with the problem. The American Association on Mental Deficiency, Council for Exceptional Children, and other professional organizations have given increasing impetus and leadership in the growth and quality of scientific and professional activity in mental retardation. Research personnel in a wide variety of disciplines have turned to the investigations necessary for the prevention and amelioration of retardation. Finally, private corporate operations have entered the service field of mental retardation on either a non-profit or proprietary basis.

This great mix of contributors and participants has meant that mental retardation as a human problem has increasingly permeated the consciousness of nearly all sectors of society. This has been a big gain, but it has created a host of difficult issues which remain to be solved. The following are some examples.

Sources of Funds for Direct Services Programs, 1970 (In Millions)



Source: The Economics of Mental Retardation, Ronald W. Conley, Johns Hopkins University Press, 1973.

The Federal Role. Some programs of the Federal Government are designed as short-term stimulation to the States or assistance in the resolution of a short-term need. Other functions are long-term and become permanent fixtures in governmental operations. What is the case with mental retardation? Although some programs have accomplished their specific goals and others have moved through initial tc succeeding phases, it is of critical importance that the Federal Government remain strongly involved in both the initiation and the support of mental retardation programs on a broad front. At the present time, approximately 22 Federal departments or agencies have programs relating to mental retardation. The largest number are in the Department of Health, Education, and Welfare, but significant activities are developing in Housing and Urban Development, Labor, Justice, Interior, and a number of independent agencies. The States are picking up on many Federally initiated programs as required by regulations. Many of the programs are too new to have achieved stability, many are subject to easy abandonment, because of competing pressures for funds if the Federal effort is prematurely relaxed. The movement to the crest of the hill requires a continued momentum, especially during the current period of economic stress. During the past quarter-century, that momentum has increased, progress in meeting the challenge of this greatest source of handicap in human development has been great. But if relaxation of effort now should weaken the foundations on which the future must be built, it might take generations to retrieve the loss.

Most urgent issues of Federal support and funding center in coordination, efficiency, accountability, and organization, in order to sustain the most cost-effective program operation. Other specific issues involve the following:

- Income maintenance is a permanent Federal responsibility shared with the States in direct support programs, and administered directly as trustee in the insurance-based programs. What will be the direction of movement with respect to the handicapped, especially of those who cannot respond to work-incentive regulations? Will there be increase or decrease in social security measures applicable to them, or shifts in the balance of responsibility?

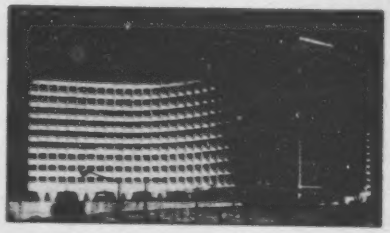
• Federal support of education has grown in all phases, including education of the handicapped and training of educators of the handicapped. One direction is certain: programs will be less categorical within the handicapped area, and probably within all education. How much of the current support will be shifted to the States? How long will the Federal Government continue to support manpower development? What degree of control by regulation will be maintained? The legislation resulting from litigation is moving towards greater Federal involvement in guaranteeing equal educational opportunity for all handicapped persons—will this include support for the necessary research and field-testing of new programs and techniques?

• The Developmental Disabilities program was designed to be a stimulus to State development, supplying funding for special and time-limited purposes. What future directions will it take? It now has increased responsibility and authorization for University Affiliated Facility (UAF) programs, but supplies at present only a minor share of the funding. There are many issues relating to the UAFs and their role in developing manpower adequately trained and necessary to the service and research tasks that lie ahead. The coordination of many Federal agencies, State, university and private sources of support, effective and realistic manpower planning and equitable geographic distribution will be critical. The 1975 Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103) added significant responsibility for maintenance of quality and protection of individual rights in services to the developmentally disabled; the implementation of these responsibilities is of greatest concern.

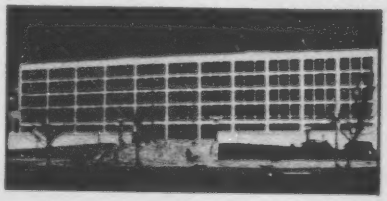
• The balance of biomedical and behavioral research in mental retardation is unstable. Shifts are taking place in the objectives and perspectives of research agencies. Will the two members of this partnership proceed through their present stage of "engagement" to a state of "matrimony," or will they go their separate ways, leaving a schism in our knowledge of mental retardation and of retarded people? If the Federal Government reduces its support of research and of training professional manpower will any other source take up the slack?

• There is much discussion both in the States and in Federal circles regarding health care needs and services and their distribution to all segments of the population. Will the mounting costs be held within bounds? Will National Health Insurance provide equitably for the poor, the handicapped, the non-working, the minimally productive? What system of financing national health care is most feasible and how can it be developed on a timely basis? Similar issues relate to the intricate problems of social service and rehabilitation. It is difficult to see how adequate levels and equitable distribution of these vital sources of human support can be maintained without the continued strong role of the Federal Government.

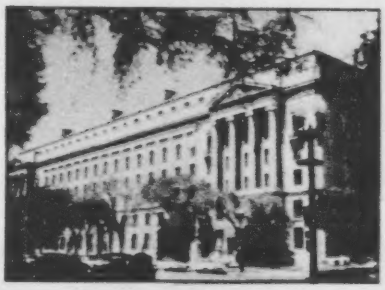
• The movement of the retarded from institution to community requires housing. What models are being developed? What role can the Department of Housing and Urban Development play in making better and more diversified living arrangements available to mentally retarded citizens?



• The Department of Labor has responsibilities that touch deeply upon the working lives of retarded people. What affiliations are being developed with vocational rehabilitation? What monitoring will take place to protect retarded workers from peonage?



• The Department of Justice is concerned with violation of constitutional rights and the protection of persons in the exercise of rights. What further steps can it take to ensure the retarded citizen his citizenship in fact?



• The root cause of mild "cultural-familial" retardation lies in the "environment of poverty." What steps can the Federal Government take in concert with State and municipalities to deal with this massive problem? The alternative for mental retardation is to deal with individual families and children, trying to salvage as many children as possible from the debilitating effects of an environment of hopelessness and despair.

The role of States. The issues that appear paramount in the States are those which involve the effective organization, funding, and delivery of services responsive to human needs.

The States have undertaken extensive planning and reorganization of services relating to mentally retarded and otherwise disabled people during the past 10 years. Much of this has been in response to local public demand but it also has reflected the stimulus and incentives provided by the Federal Government. It has been linked to the cumulative pressures for reform in the overall massive and difficult problems of providing adequate health, social, and educational services to all constituencies at need. The growth of State budgets and State administrative apparatus to manage these problems has been massive, the competition of interests has been severe, the outcomes from State to State highly varied, but on the whole, extensive progress has been made. The needs of mentally retarded people have been addressed, both generically within overall agency development and categorically as a special aspect of need. The President's Committee on Mental Retardation has undertaken a survey of these developments, to be reported in a companion volume to this Report. The following issues are seen as most central to the States' role in meeting the problems of mental retardation in the next quarter-century.

• The organization of State services must clearly identify and coordinate responsibility for problems of mental retardation and developmental disabilities. This requires consolidation of administrative authority, with the establishment of centralized human services agencies and decentralization of operations, provisions for State planning, development and accountable review.

• The elaboration of regional and local service patterns. The objective here is to reflect local needs and provide appropriate local management under overall State authority. The distribution of services on an equitable and accessible basis, particularly providing for depressed, isolated, or otherwise underserved populations is a problem which requires the most careful balance of Federal, State, and local initiatives and resources.

• The evolution of State budgetary management to reflect the evolution of service delivery concepts affecting mentally retarded persons. This centers in the issues surrounding "deinstitutionalization." As indicated earlier, the core of this problem is the development of a sufficient array of local community services to enable retarded children and adults to remain in their own or alternative homes in the community or to return to the community from institutional residence. At the same time, there is an urgent need to improve the standards of care and service in the institutions so long as they are serving a useful and necessary function. The transition from institution-centered to community-centered State services creates a fiscal conflict which must be resolved if progress is to be made. Currently, the

support of services in many communities is lagging because of massively increased supports to the institutions in order to qualify as Medicaid-eligible intermediate care facilities under Title XIX of the Social Security Act, or in response to actual or threatened litigation. The net effect, if the wrong trends develop, could be the reinforcement of the institutional model at impossible levels of cost and serving only a fraction of the population in need.

The resolution of this issue calls for careful coordination and reconciliation of Federal policies and programs which may be in conflicting directions; careful State planning, utilizing the Developmental Disabilities Advisory Councils and other mechanisms for planning and evaluation; and judicious decisions on budgetary allocations which foster the growth of community services while upgrading quality in the role of the institutions as transitional facilities to be recast in new roles or eventually phased out.

• Interstate agreements on collaborative, cooperative, and cost-sharing problems. This includes continuity of service as consumers move across State boundaries, financial and legal jurisdiction in the placement of clients for service across State lines, the regional provision of services at the intersection of State boundaries.

• The balance of service components embodied in generic and specialized agencies and delivered through channels consistent with the character and needs of local and regional communities. This includes the evolution of improved forms and patterns of service delivery in the areas of education, rehabilitation, residential services, health services and a variety of facilitative services such as transportation and communication.

• The protection of legal and civil rights of the mentally retarded through statutory revision, mechanisms of advocacy and appeal, and the promulgation of standards identifying and establishing the rights and responsibilities of disabled citizens and the agencies charged with their care.

The role of private organizations and individual volunteers. In the field of mental retardation, a broad range of private groups and organizations exert considerable influence on the course of events. These may be divided into six principal divisions: a) advocacy groups representing the consumer of services, the retarded citizens and their families, of which the National Association for Retarded Citizens is the principal example; b) private foundations and service clubs, such as the Joseph P. Kennedy, Jr. Foundation and the Jaycees and Civitan Clubs, which direct substantial financial resources to the promotion of specific objectives; c) professional groups and organizations representing those who are expertly qualified to develop and apply the knowledge and technology required to meet the problems of mental retardation, of which the American Association on Mental Deficiency and the Council for Exceptional Children are prime examples; d) special interest groups which have a stake in the programs for the mentally retarded, but are primarily concerned with the protection of their own interests as participants in the service delivery programs, of which the unions and employee bargaining agents in institutions and other settings are examples; e) private service suppliers conducting either non-profit or proprietary operations in the field, of which private residential schools, foster homes and group homes for retarded children and adults, or the host of nursing homes admitting retarded citizens, are examples, and f) organizations of retarded persons themselves, such as We Are People First, which has emerged in Oregon and shows signs of spreading.

• The National Association for Retarded Citizens came into existence in 1950 as the collective voice of the parents of retarded children and others deeply concerned with the appalling state of public institutions and the lack of other developmental and supportive opportunities for mentally retarded individuals in society. NARC was greatly instrumental in initiating, demon-

strating, and procuring special education, diagnostic and evaluation, vocational rehabilitation and other services, in provoking institutional reform and in changing public attitudes towards mentally retarded and handicapped persons. Through the succeeding quarter-century it has grown in size and stature and has evolved changing roles as the professional and governmental sectors, backed by growing public interest, assumed increasing responsibility for the well-being of retarded citizens.

Throughout its history, NARC has emphasized public education and stimulation as its principal role. This has expressed itself in extensive public information programs through all media, through innovation and demonstration of service programs of all forms, through political pressure at all levels, and through participation in a wide range of consultative, advisory, and advocacy activities. More recently it has fostered programs of personal advocacy for retarded individuals and has initiated and participated in litigation in behalf of class-rights of retarded citizens. Local member associations have in varying degrees gone beyond service innovation and demonstration to develop a continuing role in service provision. This has been the source of continuing debate in NARC, with national policy emphasizing the primacy of "obtaining" over "providing" direct service.

Programmatic issues which NARC projects to 1979, include the following goals:

•• Achieve increasingly adequate, consistent, levels of funding of all services needed by retarded persons and their families.

•• Reduce the incidence of mental retardation from specific identifiable conditions such as malnutrition, infections, environmental toxins, genetic conditions, and environmental deprivation.

•• Achieve an array of developmental institutional and community-based residential services for all retarded persons, ensuring possibility of choice among a series of desirable alternatives.

•• Increase the quantity and quality of research impacting upon prevention and amelioration.

•• Ensure the legal rights of all mentally retarded persons in every State, working with appropriate individuals and public and private bodies.

•• Establish effective advocacy systems throughout the country in cooperation with interested groups and individuals to serve all mentally retarded persons, and to support, monitor and evaluate all service impacting on such persons.

•• Achieve appropriate educational preschool and continuing education services for all mentally retarded persons of all ages.

•• Foster and/or develop demonstration models of comprehensive community services for mentally retarded persons within any specified area, including sparsely populated rural areas.

•• Significantly increase the number of mentally retarded persons employed and improve their level of employment and expand vocational and prevocational training.

•• Improve the understanding and acceptance of, and commitment to, the cause of mental retardation by the general public and by specific target groups (e.g., physicians, judges, attorneys, legislators, and public school administrators).

• The Joseph P. Kennedy, Jr. Foundation. Among private foundations, the Kennedy Foundation has been outstanding in the use of its funds to promote human well-being through support of basic and applied research, professional training, ameliorative service directed to the problems of mental retardation. The Foundation has contributed over $10 million to the construction of university centers, has made five series of International Awards to individuals and organizations for leadership and achievement in the field of mental retardation, has conceived and developed the Special Olympics and the "Families Play to Grow" programs to stimulate physical and recreational development in the mentally retarded, and has stimu-

lated national concern for problems of medical ethics associated with mental retardation. The role of such private effort is of great significance as the ally of public efforts and programs in the field. It helps to maintain an essential balance in reaching towards the goals of prevention and alleviation of these handicapping conditions.

Current issues relating to the role of foundations in the national effort include:

•• The coordination of public and private efforts in a mutually supporting rather than competitive relationship. The Kennedy Foundation has exemplified how well this can be done when goals are clarified and well defined.

•• The involvement of more foundations in contributing to the problems of human disability.

•• The interlocking of the efforts of foundations devoted to related types of disability into a coordinated attack on the total array of mutual concern.

• The American Association on Mental Deficiency (AAMD) and the Council for Exceptional Children (CEC), especially its Mental Retardation Division, exemplify the necessary component of professional organization in the united national attack on the problems of mental retardation. Both AAMD and CEC maintain close contact with governmental affairs, especially in Washington, and are influential in the development of forward-moving legislation and the program development of executive agencies. Both have been deeply involved in the development of standards, for professional preparation, performance and conduct by individuals working in the field, as well as for the operation and performance of schools, institutions and other services and training facilities.

CEC has summarized its view of the future dimensions of its role in the following terms:

•• Continuation and enlargement of joint efforts with State and Federal agencies and with non-governmental agencies in all areas involving education of the handicapped.

•• Enlargement of the concept of child to extend the role of the organization to a concern for the rights and the developmental advancement of all those who differ from the normal, whether legally "children" or not.

•• Attention to the specific issues of "mainstreaming," improving teacher education, effects of litigation and legislation, accountability, innovative use of limited resources, precise individual assessment, and the demonstration of program effectiveness.

AAMD has in recent years addressed itself through position and policy statements to issues which will continue to be focal targets. These include problems of definition, classification and epidemiology; the rights of mentally retarded persons; standards for residential and community based services. The Association has been involved in a series of landmark class action suits involving the interests of the retarded as *amicus curiae*, plaintiff, advisor to the court, or in the provision of expert witnesses. Wide affiliations are maintained with all organizations, commissions, agencies and groups having an interest in mental retardation or in the well-being of mentally retarded individuals.

AAMD is currently involved in the following major issues of concern:

•• The use and misuse of behavior-modifying drugs prescribed for mentally retarded people.

•• The use and misuse of behavioral technologies on mentally retarded people.

•• The establishment of an adequate national data base in mental retardation and the issues involved in individual rosters of retarded people.

Looking toward the future, AAMD sees the following trends

as focal points for issues on which AAMD is prepared to make its contribution in collaboration with others:

•• Addition of large numbers of professionals to programs for mentally retarded persons.

•• Integration of retarded people into general service delivery systems.

•• Reduction in categorical funding.

•• Increasing costs of programs.

•• Drastic changes in both institutional and community programs.

•• Labeling becoming suspect and possibly being declared unconstitutional.

•• Exclusionary policies in service delivery.

•• Changes in parental and community attitudes to allow a more normal life for retarded people.

•• More accountability in service systems.

•• Extensive monitoring of program systems by lay advocates.

•• Institutional problems and abuses being transferred to community programs.

•• Earlier detection, eliminating in many cases the symptoms of retardation.

•• Legal resolution of the issue of euthanasia.

•• Clarification and monitoring of the boundaries of competent and ethical professional practice.

• An example of a special interest group is the American Federation of State, County, and Municipal Employees. Initially, it supported deinstitutionalization. Then it opposed the process because of what it considered to be unplanned "dumping" of residents, but continued to show interest in the development of community services and the retraining of institutional workers.

• Private service delivery systems and agencies. These operations fall broadly into two groups: non-profit and proprietary, including small-scale alternative service operations purchased for a fee.

Non-profit agencies are generally under the sponsorship of religious groups, service organizations, and associations for retarded citizens, or incorporated Boards instigated by the ARCs. The long-established and prestigious private schools and homes for retarded citizens are generally not heavily endowed and depend upon high fees in order to provide top-quality services. In the main they are available only to families of wealth. Religious agencies are limited in the public funds they can receive, depend heavily on donations and contributions and fees. They may or may not maintain acceptable standards of services. Agencies operated or sponsored by ARCs are generally small group residential homes or day services. They commonly receive public funds as well as contributed funds, frequently under community united fund sponsorship. They represent a wide range in quality, resources, program, and size. They usually form a link in the system of community services, but coordination within the system may be very tenuous. Some such operations constitute comprehensive service systems in their own right, with highly qualified staffs and impressive resources.

Nursing homes have been used in recent years, first to take up cases on the waiting list for institutional admission and more recently as recipients of placement by institutions seeking to reduce their population. Although proprietary nursing homes have been the object of considerable unfavorable attention recently, most of them operate according to acceptable standards and at reasonable cost. The basic issue in that they are established to provide medically related care to aged and infirm person. They may not be at all equipped to provide the services needed by retarded citizens who do not have chronic medical problems.

In general, the issues relating to private service providers fall under the following considerations:

•• The issues of cost-benefits; this includes the elements of income, including fees related to the quality, accessibility, and appropriateness of service.

•• The issues of appropriateness of service to individual need.

•• The issues of inclusion within comprehensive service delivery systems with some accountability to the standards of such systems.

• Organizations of retarded persons speaking for themselves are beginning to emerge. They can be expected to offer an important added voice in policy decisions that too often have been made by persons unable to imagine the full potential of retarded citizens. As was said of one retarded individual who surprised everyone by succeeding in office work, "You never know how far a person can go—once she decides she wants to go there."

The role of non-governmental elements in the total arena of mental retardation is of great importance. Without them, bureaucracy would be unbounded, and in fact would quickly reduce its concern for mentally retarded persons to the simplest and most "cost-effective" means of sweeping it under the rug. The ultimate issue is, therefore, a partnership of governmental and non-governmental resources and responsibilities, which is, after all, the main shape of a democracy.

The issues delineated in this chapter lead to a consideration of what is possible and feasible in the kind of world that is unfolding for us. The future will not be built by our wishes, or even by our resolution, but by effort that takes full account of what is possible. What can we read in the face of the future that may tell us what can be done?

Chapter 2

The Face of the Future

"How we now conceptualize the problem of MR and plan to deal with it in the future is an indication of how we will implement or ignore to our peril the cooperative basic law of life. Thus, for me, MR management may be a harbinger of human survival or extinction."

"Two major aspects of change have become increasingly visible. One is the explosive growth in human actual or potential capacities to intervene in larger environmental processes, both physical and social . . . capable of affecting the physical balance of life on the planet itself, and reaching into every aspect of individual life and societal institution . . . The other is the lag in the conceptual grasp of this transformation . . . and in the understanding of the psychosocial processes by which we may manage its changes more effectively. In both cases, the conceptual grasp of the rate and magnitude of ongoing changes and their potential longer range consequences has emerged as one of our most critical social imperatives."

McHale[1]

In view of our present concern with the problems of mental retardation, it may seem presumptuous to place that fragment of the human condition into such an awesome cosmic setting as the preceding comments imply. Yet the necessity to do so is inescapable. The goals of reducing the occurrence of developmental disabilities and of ameliorating the effects of such disabilities are tied inexorably to the total effort of mankind to make and preserve a world that is tolerable to human life and conducive to human happiness.

". . . How we now conceptualize the problem of MR and plan to deal with it in the future is an indication of how we will implement or ignore to our peril, the cooperative basic law of life. Thus, for me, MR management may be a harbinger of human survival or extinction."

Gorney

Because mental retardation is intertwined with so many facets of social, economic, political, and biological life, and its management depends so deeply on the evolution of our total human situation, the President's Committee sought assistance in estimating the probable circumstances that will shape the future. It engaged a group of experts in the analysis and projection of social change, and held two conferences with them and a group of selected experts in mental retardation. The first conference, at Asilomar, California, December 9 and 10, 1974, was to orient the groups to one another's interests and points of view. Thereafter, the six futurist consultants prepared working papers [2] dealing with the key events and trends which will affect society in the next 25 years and offering forecasts of their impact on the problems of mental retar-

[1] For full names and organizational connections of "futurists" quoted, see list at end of chapter.

[2] The six papers and an interpretative chapter will be published at a later date by Plenum Publishing Co., New York. They are not available from PCMR except as summarized in this chapter.

dation. These papers served as the basis for discussion and analysis by the same participants at a second conference, held at Dulles Airport, Virginia, February 25 and 26, 1975. The discussion provided background for the formulation of goals, objectives and implementing recommendations by the PCMR task groups assigned to major aspects of the report. It should be emphasized that each of the six papers prepared by the futurists was an individual effort; that no single consensus emerged in their projections to the year 2000; that while there were strong points of agreement and convergence, no "official" view of the future was adopted by PCMR. Nevertheless, all participants were stimulated by the presentations and discussions. The reports of the task groups, later approved by the full Committee, undoubtedly reflected the discussions and the presentations of the conference.

The following statement will attempt to abstract and summarize the principal outcomes of the Futures Project, from the various papers, discussions and subsequent contributions by participants. Topically, we will proceed from some reflections on the nature of social forecasting, to some of the particular trends seen as reasonably firm, together with some of the long-range possibilities envisioned by the principal consultants, the implications of these projections for the problem of mental retardation, and finally their implications with respect to possible governmental initiatives.

The Limits of Forecasting the Future

Future studies have inherent limitations which must be understood if they are to be of value. One fundamental limitation is uncertainty. Predictions, at best, are estimates of probability based on what is known but always subject to the intervention of what is unknown. If it is possible to estimate variables that *might* intervene, such as political decisions on critical issues, then one may project alternative possible futures and the consequences that would probably flow from them. The PCMR consultants were all agreed that the complexities and rates of change in present society make it particularly difficult to forecast with assurance, but, on the other hand make the delineation of alternative possibilities that much more urgent.

They further agreed that the extrapolation of trends taken in isolation is especially precarious and usually futile, because so many trends quickly approach limiting conditions which make them irrelevant. For example, world population, if extrapolated from the 1650 to 1972 trend, would reach infinite size before 2025! The world will *not* have an infinitely large population—limiting conditions will intervene to alter the trend.

"Some of the most valuable forecasts are not those that are most accurate but those which prove to be self-defeating or self-fulfilling. As an example, the currently popular limits of growth forecasts are hopefully self-defeating. They indicate that, if present trends continue, catastrophic situations will occur in the next century. Such a forecast is designed to serve as an early warning system to encourage more careful analysis and consideration of changes which will prevent the continuation of the trends shown."

Linstone

The role of future projections is to anticipate the consequences of alternative courses of present action.

"Their central purpose is not to predict what *a* future or *the* future will be, but rather to explore in conjectural form various future states which remain open to change, are resultant upon our individual and collective actions, and which are accessible to human choice. The emphasis is non-deterministic."

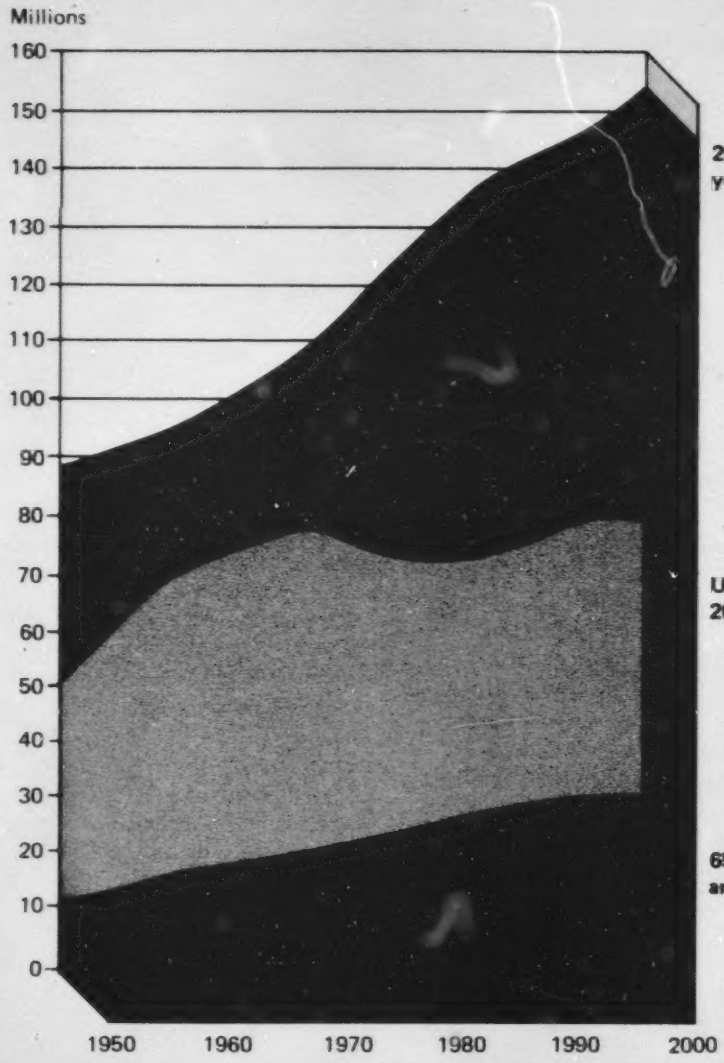
McHale

In this sense, none of the consultants took a hard deterministic line, but emphasized the critical role which decision-making has on future outcomes.

"Conjecturing about the future . . . *must* go beyond the facts . . .
The attempt is to find ways of connecting the present with *more*

Actual and Projected Population, By Age: 1950-2000

Assuming 2.1 Children per Woman



Source: Bureau of the Census.

desirable futures, rather than *less* desirable ones."

Adelson

and we are warned that

"Our piecemeal, band-aid approach [to the problems of pending crisis] will not do the trick. Much of our talent is dissipated in "rearranging the deck chairs on the Titanic."

Linstone

The Next Twenty-Five Years

Although the experts differed in their estimates of the time it would take to resolve the present economic difficulties, they were all of the opinion that the crises of energy, shortages of resources, unemployment and rampant inflation are temporary and will be brought under control. They recognized that the political problems involved would be difficult and tension-breeding, but on the whole they were surprisingly optimistic in anticipating the resolution of crisis politics into more stable conditions of long-term development.

General Living Conditions

Combining trends in birth rates, age of marriage, longevity trends, and mortality rates, the U.S. population will be made up of more household units of smaller size, leveling off to a total of approximately 264 million people by the year 2000.

The urbanization of American life will largely continue, with a smaller counter movement toward return to country living and a simpler life. The metropolitan centers, however, will spread to larger and denser areas surrounding the central core, which will diminish in density and improve in quality.

Multiple-unit dwellings will continue to replace single-family houses, and with a decentralization of industrial and commercial enterprise, people will tend to live nearer their place of work. Thus cities will become clusters of relatively self-contained residential-economic centers, with service and recreational functions being organized on the basis of these centers.

Transportation will be easier, with greater over-all mobility, but will be held in balance to finite energy resources. Public transportation will be more available and accessible, operating on a low-fare tax-supported basis, but will not displace the automobile. Cars will be smaller in size and more economical and efficient, with better pollution control. In general, despite increased population densities, air and water pollution will be better controlled and reduced by as much as 50 percent in the next 25 years. Alternative fuels and improved technology in the design of automobiles will reduce their pollution hazard. But they will be more costly, and the mode will be one car per family; with greater reliance in urban areas on a variety of alternative forms of transit. Under the condition of long-range energy resource limitations, it is highly probable that the needs for transportation in terms of the movements of physical mass will be offset by anticipated technological improvements in communication—for example, home computer terminals connected with stores and banks.

Most demographers predict a rise in the median age of the population by 2000 from 28.1 to 34-36, depending on the birth rate. If families average 2.1 children, the total population under 15 years will increase by only 5% by the year 2000, or it could actually decrease by 11% if families average only 1.8 children. The demographers anticipate that the small family size is here to stay, based on progress in methods of birth control, economic benefits, role aspirations of women, concern over the effects of unrestrained population growth on consumption of scarce resources, and the effects of free clinics, sex education, and legally approved abortions on the number of unwanted children.

These demographic predictions have obvious implications for mental retardation. Fewer and better controlled pregnancies can greatly reduce the incidence of mental and physical disability. Smaller family size can reduce poverty and lack of infant stimulation by the parent, both of which contribute to socio-familial retardation. The reduction in incidence results in increase in the average age of the mentally retarded population, requiring a different mix of services, with greater emphasis on the retarded adult. This, in turn, bears heavily on the problems of public acceptance.

A trend toward more self-contained community areas within increasingly urbanized society entails many consequences.

"One very important aspect. . . is an increase in community-based activities deriving at least partly from the difficulty of transportation in an energy-short society. For some reasonable period we can expect transportation to become increasingly expensive and difficult. One result of this will be the development of activities—work, leisure, and cultural—which focus more on people who are co-located geographically within a region, within a section of a city, and so on . . . Such arrangements . . . will get people who live close together actually to interact together, and this may strengthen the basis of community feeling, understanding, and mutual supportiveness . . . Emphasis may shift a little toward the more neglected components of human values that appear to be gaining prominence in some quarters, by comparison with the crass utilitarian values that have been dominant in the society for some

time now. An environment in which neighborhoods become communities . . . can be expected to be much more amenable to the integration of people whose *economic* productivity is below par."

Adelson

The Economy

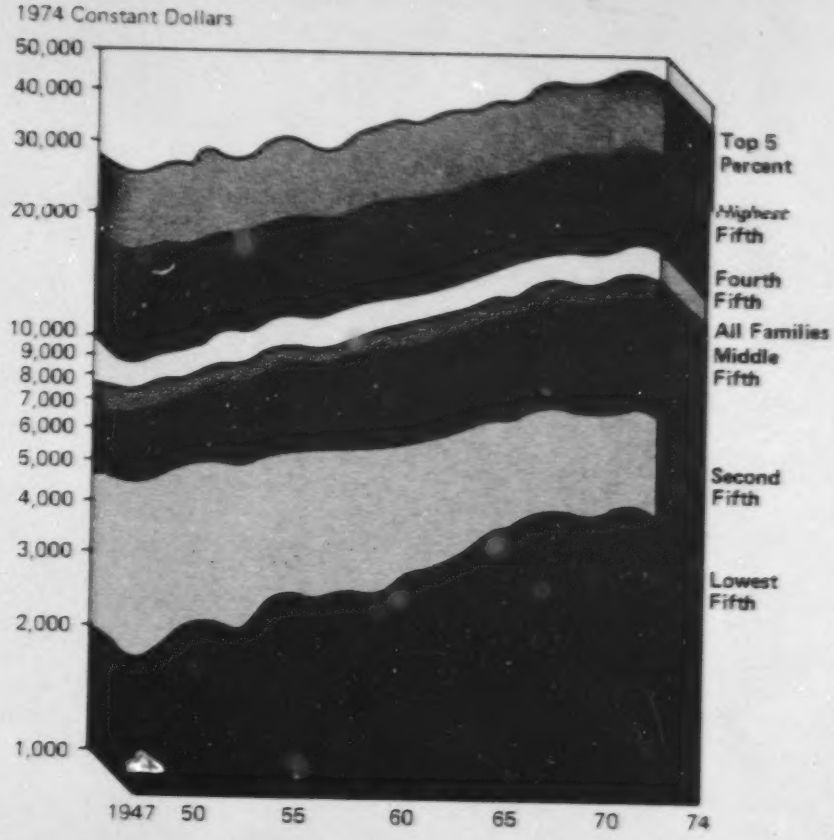
All projections for the future forecast continued economic growth, with some improvement in living standards but at a slower rate. Energy shortages are not expected to be a long-term limiting factor on growth. Current energy dislocations are expected to be temporary in the United States as technology makes alternative sources available (coal and coal gasification, nuclear energy, geo-thermal and solar energy). The period of transition will involve a variety of social and economic pressures which will be reflected in political activity, and probably will be followed by long-term limitations on energy use.

In terms of GNP the economy grew 128 percent in the past 25 years, and may be expected to grow almost at the same rate in the next twenty-five. It is anticipated that the present trend toward greater relative increase in production of services over production of goods will continue, with the present ratio of about 55 percent of the labor force involved in the production of services going to something like 70 percent. This is a measure of the continued increase in technological productivity and goes together with the steadily decreasing work week, early retirement and delayed entry into the work force.

The vaunted "green revolution" in agriculture, hailed as a model of the growth of efficiency in production, may be largely illusory. Machines have replaced man to the extent that 4% of the population now produces vastly more food and fiber than 60% of the population did three generations ago. That may be one measure of efficiency. However, agriculture is in perennial economic trouble because in energy terms it is grossly inefficient! In replacing the man with a hoe by a tractor, it now requires 5 BTU of fuel energy to produce 1 BTU of food energy. As the cost of fossil fuel energy increases, the efficiency of U.S. agriculture in terms of energy exchange decreases. This produces a chronic agricultural crisis in relation to the total economy, and may require a quite new approach to manpower use in agricultural production. Conceivably this could benefit retarded persons, who always have taken well to farm work.

These economic indicators led several of the futurist consultants to suggest that we are approaching a major economic turning point in human history—from a basis of scarcity to one of relative sufficiency. If this is the case, then the long-term consequences in terms of social values

Families Ranked By Size of Income: 1947-1974 (1974 Constant Dollars)



Source: Bureau of the Census.

and institutions are incalculable. If the GNP continues to double every two decades,

"We will have to learn how to define progress in American society in some terms other than economic growth because in a world increasingly dominated by resource scarcities and ecological concerns, it may not even be possible, let alone desirable, to continue to aspire to ever higher standards of production and consumption, and to measure progress or evolution in these terms alone. The most optimistic have suggested that progress may come to be measured in terms associated with ecology and humanism as much as economic well-being, so as to take account of the satisfaction of non-economic human needs."

Nanus

What becomes of poverty if a stage of economic sufficiency is achieved? The question of poverty is two sided. *Absolute* poverty is officially measured in the United States as a fixed standard of real income based upon the prevailing cost of a minimum human diet. The percent of the population below this level has declined from 22.4 in 1959 to 11.9 in 197[illegible]. However, the proportionate distribution of incomes in American society has changed very little in that time, with the lowest fifth of the population receiving a steady 4.5 to 5.5 percent of the aggregate income in each year in the United States from 1947 to 1972. This creates, the futurists suggest, a persistent condition of *relative* poverty. Projection of the continued decline of absolute poverty to near-zero could still leave the

level of relative poverty unchanged. If, as some analysts maintain, the socially deleterious consequences of poverty, including socio-familial mental retardation, arise, not primarily from lack of food itself but from the status position of poor people in society, those harmful consequences might continue.

Looking further at the economic future, it appears likely that more restrictions will be placed upon business operations by the courts, by consumer activist groups and by the government. They may make it more difficult for the traditional forms of small business to survive, allowing big business, especially international big business, to get bigger. The big corporations, however, may increasingly decentralize their operations, corresponding to demographic developments, and small community enterprises designed on quite new models may develop as an expression of new consumer needs and work mores under the surface of large scale industry and commerce.

The indicators of present movement point to industrial and commercial enterprise organized on an increasingly large and international scale, with an expanding export of production to cheaper labor markets. Domestically, however, business and industry will operate under increasing constraints with respect to personnel and employment policies, development programs for the underemployed and unemployed, job satisfaction programs, consumer accountability and pollution-free conditions. A constrant favorable to employment of retarded persons already has come on the scene through a new law requiring Federal contractors to have affirmative action plans for hiring the handicapped. Technological improvments will provide a sufficiency of material goods produced by a decreasing percentage of the labor force, with an increasing proportion of manpower involved in service-related employment. If these developments are indeed in the future, then American society may be on the verge of a major transition to a new stage in its evolution. Daniel Bell describes three successive phases of societal development:

". . . A pre-industrial society is essentially one based on raw materials as a game against nature in which there are diminishing returns. An industrial society is organized primarily around energy and the use of energy for the productivity of goods. A post-industrial society is organized around information utilization . . . as a way of guiding society."

The trends indicated by the consultants at PCMR's Futurist Conference appear to be in the direction of a post-industrial society in the United States. Other advanced nations appear to be still in the industrial phase, some of them with difficulties in the way of further advancement. A large part of the world is only beginning to emerge from the pre-industrial society.

The full implications of such a major transition in American society are uncertain, but they would entail significant realignments in the socioeconomic patterns of work and leisure. Average income may well rise to double its present level, partly as inflation but representing also a rise in real earnings. The tax bite on the paycheck will likely be larger from all levels of government but residual buying power will still be improved for all economic groups. In the year 2000, the largest number of Americans in the work force will be between ages 35 and 45, providing a sufficiently large tax base to support a variety of public programs. The leveling birthrate, and increasing average age of the population may, by the generation *following* the year 2000, yield a considerably smaller work force to support a larger retired population. This will require further shifts in the socioeconomic structure.

The average work week is expected to decline to 35 hours or less by 1990 and 30 hours by 2000 with corresponding increase in number of paid vacation days. Some form of baseline annual income for all Americans is considered a distinct probability by 1990 while one study indicates a move towards expanded income maintenance as early as 1980. There was gen-

eral agreement that the quality of life on the job would be of central concern. With shifting population and economic growth trends, the probability of sufficient jobs for all is high, but with increasing requirements of knowledge as a qualification for upward mobility. One consultant emphasized a trend toward employment recycling, or a succession of careers geared to changing job markets and continuing educational opportunity; another foresaw the emphasis on maximizing human potential as a growing social policy beyond the merely economic goal of full employment. This assumed a growing shift from an economy of job scarcity to one of job abundance, coupled with basic economic sufficiency.

All forecasts hazarded by the futurist consultants assumed that the advancement of technology would continue, that the current crises of energy, unemployment and rampant inflation would be controlled, that international events, although threatening, would not produce cataclysmic conflict, and that the role of government would be consistent with the development of these trends. What implications for mental retardation did the futurist consultants see in these projections of economic and social conditions?

Mental Retardation and the Future

There is no assurance of automatic improvement of the social problems of mental retardation or of the condition of life for retarded people in the decades ahead. The general social and economic outlook provides some factors potentially highly favorable to their advancement, but suggests others that would be unfavorable if not anticipated and offset.

Prevention

A reduction in the incidence of mental retardation from biomedical causes is highly probable in the next two or three decades on the basis of two considerations.

• If the birth rate remains low or continues to decline, through family planning and controlled pregnancies, it will not only yield a lower gross number of developmentally disabled babies, but will provide greater opportunity for pregnancy and childbirth to occur under optimal conditions. If maternal and child health services and genetic counseling services continue to develop, and especially if they are accessible to poor families living in hazardous environments, the chances of avoiding accident or injury and of treating threatening conditions are greatly increased.

• The advancement of science and technology can yield new methods of prevention and treatment, even of restoration of function. The probable advancements include:

•• Increased capability of detecting the presence or *absence* of abnormal conditions during pregnancy.

•• Improved capability for precisely informed genetic counseling.

•• Increased understanding of pharmacology and its effects on broad aspects of human functioning, including intellectual and emotional behavior.

•• Computerized and automated health screening and diagnostic clinics, with early detection and treatment of a wider range of inborn errors.

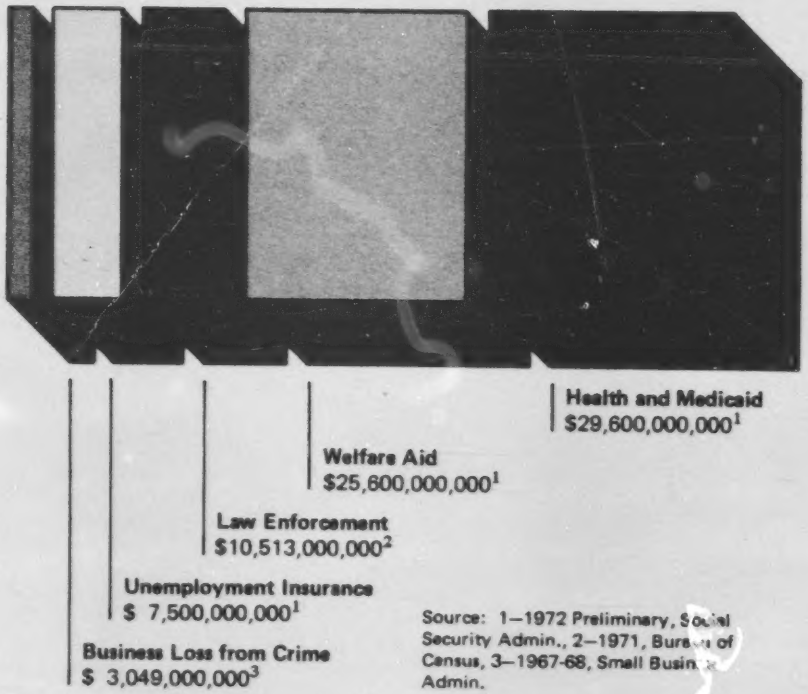
•• Knowledge of cell reproduction which might provide the means not only of controlling undesired wild growth (cancer) but of desired patterned growth (repair of the central nervous system).

The realization of these advancements could easily reduce the incidence of biological mental retardation by more than the goal of 50% by the year 2000.

Sociocultural Forms

The prevention of sociocultural mental retardation is much more uncertain. Its roots are more complex and less well understood. We know it is associated with poverty, cultural disadvantage, and deteriorated family life. If the forecast of a substantial reduction in the number of families below officially defined poverty level is accurate, this could at least reduce haz-

Costs Deriving from Poverty



Source: 1—1972 Preliminary, Social Security Admin., 2—1971, Bureau of Census, 3—1967-68, Small Business Admin.

". . . Coalitions with others concerned with the products of poverty will be needed. When the social costs of mental retardation are added to those of high juvenile crime rates, runaway welfare costs, high unemployment, poor productivity, excessive medical costs due to prolonged neglect and disease, suicides, broken homes, and a host of other real social and economic costs deriving from the culture of poverty, perhaps a strong argument can be made for raising this cause to a high priority agenda item for the nation."

Nanus

The outcome depends on distribution of opportunity and the evolution of life styles among those segments of the population now in the poverty sector.

"As the local society moves towards higher standards of living (notwithstanding the present economic crises) we may expect, for example, that the incidence of socio-environmental retardation could reasonably drop by one-third in the next 10-20 years. The 'trends' are not inevitable in this regard, but depend centrally on collective human decisions and actions towards ensuring the spread and maintenance of better styles of life."

McHale

ards associated with material insufficiencies. It is questionable whether this would reach the root of the problem, which evidence suggests is embedded in the "relative poverty" or the status of poor people in relation to the social mainstream.

"Which is more important absolute or relative incomes—from the viewpoint of mental retardation? The evidence suggests both are important, but recent findings point more to the latter. There is a strong implication that PCMR policy should be oriented primarily to the impact of the culture of poverty regardless of whether the incomes of the poor reach a level to permit adequate consumption with regard to food, housing, and health care . . . One must look for a concerted, large-scale, multidimensional, and long-range attack on the culture of poverty . . ."

Nanus

What are the chances of that being done? Very low, if only mental retardation is at issue.

In summary, the consultants generally saw strong possibilities of reduction of mental retardation, contingent on three principal trends continuing over the next two or three decades:

- Reductions in population growth and family size.
- Technological advancements.
- Reduction in absolute and relative levels of poverty.

Citizenship

The current concern with the rights and interests of minority groups and individuals favors a recognition that those who are mentally retarded have a claim on equitable treatment in the community. Unless there should be a political turn toward authoritarian and repressive controls, it seems likely that the humanistic trend toward equal rights will be favorable to retarded persons.

Tendencies are apparent, and likely to continue, toward acceptance of wider ranges in lifestyles and behavior of individuals, greater tolerance for differences of appearance, greater flexibility in individual choices. While these generally make for increased tolerance of retarded people in the community, they could be accompanied by more impersonal and uncaring attitudes—a tendency for each person to "do his own thing" and not worry about what others are doing. A counter tendency to this, however, is the contemporary concern, widespread among youth, in "helping" involvements and vocations. The question is whether this will be maintained as present youth moves into middle life and sets the attitudinal atmosphere for the culture.

The futurists were inclined to see this issue as revolving around the course taken by the economy. They maintained that if conditions of scarcity and economic pressure are long continued, the sense of personal insecurity could lead to increased competitiveness, ingrouping, and a reduction of tolerance for deviation, especially when the deviant person either needs supporting service or is competing for scarce resources or jobs. On the other hand, if the economic crisis is resolved within reasonable time, and confidence in the possibility of sufficiency of resources revives, the role of retarded people, among other groups with special needs and conditions, will be much improved.

A real danger exists for mentally retarded people if the "lifeboat" theory of competitive survival is engendered by prolonged unemployment and economic crisis. Developed to its extreme, that theory condemns those who are mentally retarded to be the ultimate losers in the scramble to stay on the boat.

But there is the opposite possibility:

"To the extent that Americans become concerned with the quality of life and other humanistic considerations, the mentally retarded could benefit enormously. This could result from proportionately greater expenditures for all human services, larger numbers of volunteers and professionals to assist disabled persons, and a greater societal interest in humane services for all citizens. In fact, there is considerable evidence that this is already happening."

Nanus

"Whatever time it takes, and it may be a decade, the possibilities of relative material abundance for many more people will be more clearly perceived. The possibilities for greater attention and allocation of resources to such social problems as MR are, therefore, much better than our current crises may lead us to anticipate . . . [a] re-evaluation process, much of which has gone on in *one* generation, would lead one to expect a greater tolerance for a wider range of behaviors as the present younger generation grows towards maturity . . . These changes already impact on the mentally retarded . . . Decline of role fixity and a wider acceptance of non-stereotyped social behaviors would obviously affect the retarded. It may well alter, for example, the training towards 'normality' . . so the retarded will be less constrained towards some fixed behavioral ideals."

McHale

In fundamental respects, full citizenship for retarded people

depends upon public attitudes. What is accepted and believed by the public influences what rights and responsibilities they will allow mentally retarded people. The general cultural trend is in the hoped-for direction of a more positive image and supportive attitude towards those who are handicapped either physically or mentally.

The main conclusion of the futurist consultants with regard to the events bearing on the status of retarded people is positive and hopeful.

". . . The general trend is toward greater citizenship and other rights for mentally retarded persons. This will occur on an accelerating basis within the next quarter century. They will receive more favorable treatment from the courts, a broader variety of services from public agencies, will be able to get and hold more appropriate jobs as others move upward into more sophisticated technological positions, will be able to work more on a part-time basis and from their homes (as others around them in society will also be doing) and will obtain greater access to the public education and specialized training required for their own development."

Plog

Humane Services

The well-being of the retarded person as citizen depends on two kinds of services, those that are essentially available to and used by other people (generic services) and those that are provided to meet unusual needs (special services). To be "humane," services of either kind must provide for independence, dignity, and freedom of choice, and contribute to the human qualities of the person.

The futurist consultants noted that the volume and extent of services made available to retarded persons has increased markedly during the past 25 years, but that there are further goals to be achieved, especially in assimilating retarded people into community life. Major emphasis focused on the areas of employment, housing, and education.

Although the "work ethic" would undoubtedly undergo significant change if society moves from a basis of scarcity to a basis of relative sufficiency, as most of the consultants anticipate, work will continue to be a central value in human self-fulfillment. It must constitute, therefore, a central concern for the retarded person. To be employed is a primary source of satisfaction and a sign of social integration. Work, however, can cover a wide range between forced labor—formerly experienced by many retarded persons in institutions—work for economic survival, and work for self-fulfillment. Nanus calls the latter "total employment" and sees a social movement in this direction. The goal is not merely "a job for everyone," but employment that is meaningful, exciting and personally rewarding. This was the intent of the Work in America Task Force developed by Elliot Richardson when he was Secretary of HEW. It is represented in the development of union-management contracts relating to conditions of work, and reflected in the increased mobility (when the market allows for it) of workers from one occupation to another.

Some of the employment indicators are unfavorable to retarded workers. To the extent that jobs become more complex and intellectually demanding—a trend that several consultants see continuing—they are at a disadvantage. Outweighing this, however, is the decrease in the pool of unskilled workers, leaving opportunities for the less able.

The present trend toward exporting production jobs to cheaper labor markets, together with the increasing demand for "public" goods such as the cleanup of pollution, enhancing the living environment, and better health service, is changing the job market at an accelerated pace from goods production to service production. This means that mentally retarded persons can be better prepared for employment through training much broader than that provided in the traditional small-industry workshop. Work in food service,

maintenance, gardening, home care, animal tending, and similar traditional jobs will continue to be in demand, and new jobs in technical industries and operations involving a high degree of automation may become quite appropriate for people of limited intellectual capacity.

An increase in community-based productive activities may derive in part from the limitations of transportation in an energy-short society.

"An environment in which neighborhoods become communities through shared involvement can be expected to be much more amenable to the integration of people whose *economic* productivity is below par. Additional benefits can include locally based work opportunities which provide a sense of worth to mentally retarded persons, and the opportunity to interact with their neighbors and people they know."

Adelson

Housing is likely to change extensively in the next quarter-century with the effects of energy changes on transportation, industry, home heating and cooling, and with the trend toward greater density in the component communities of metropolitan areas. There will be more households of smaller size and varied composition, living increasingly in multiple-unit dwelling complexes. Forty to 45 percent of the housing of year 2000 is not yet built. This creates a strong possibility of incorporating technological and social supports for disabled people and people of limited capacity for independent management.

Education of mentally retarded students will show extensive utilization of new communications technology. The anticipated explosion in information technology could leave them at a disadvantage; but only if the situation is allowed to develop into a stratified society of "information haves" and "information have-nots", with retarded persons helplessly immobilized in the second category. But it need not happen that way. Retarded persons can be the beneficiaries of these technical developments:

- In making new sensory inputs and stimulus ranges possible for the severely retarded and in opening up possibilities of direct augmentation of learning for the less retarded person.

- In giving them more flexible and equitable access to available education and knowledge via more sophisticated means, such as

•• new modes of recording, coding and presenting information for specialized users.

•• new prosthetic aids to carrying out complex intellectual tasks. Computer miniaturization such as the pocket electronic calculator is still in its infancy.

•• general education itself, in which the retarded child will increasingly participate, will undergo many fundamental changes under impact of the new technologies.

•• somewhat farther ahead are possible outcomes of brain research allowing enhancement of intellectual functioning.

In addition to the impact of new technology, alternative approaches to the traditional competitive methods of the schools are possible:

". . . The tendency to promote cooperative attitudes and activities as contrasted with competitive learning behaviors . . . seems ready to permeate, to some degree, all levels of the educational process. Watching this trend could teach us how best to develop cooperative and mutually supportive skills and attitudes, so that as time passes, expectations along this line can expand even more. This attitude can make normalization of mentally retarded children more effective because they, as members of a *cooperative* group, may not need the qualifications that would make them competitively productive in the group."

Adelson

New educational approaches of benefit to mentally retarded youngsters are seen in the use of the community itself as part of the school.

"This trend has two hopeful consequences for mental retardation. The first is that it tends to emphasize knowledge by experi-

ence . . . rather than through symbolic representation . . . Secondly, the rates and kinds of stimulation that occur this way may be better attuned to the MR's."

ibid.

The comprehensive nature of service delivery systems for mentally retarded persons must be fully understood in evaluating future projections.

"Any national program must involve several human service systems. That is, retardation transcends the fields of medicine, education, employment, social welfare, or even all of these combined. No one of these alone can solve the problems of retardation. Therefore, from the start broad professional planning must involve all the social service systems in full collaboration with parents and political decision makers.

Tarjan and Keeran, quoted by McHale

Implications For Future Federal Initiatives

If, as most of the futurist consultants indicated, the United States is showing distinct signs of moving beyond the industrial to a post-industrial phase of social-economic development, some implications for the future role and function of government may be drawn and applied to the area of mental retardation. Bertram M. Gross, in summarizing key social structure changes that signalize the post-industrial phase, pointed to the following which appear especially significant:

Social Patterns: World and U.S. Social Structure

INDUSTRIAL	POST INDUSTRIAL
Specialization of labor force with declining agricultural component.	Professionalization of labor force, with at least 70% in service.
Power-driven machinery in large aggregations.	Cybernation and computerization.
Larger and more differentiated organizations.	Complex, mixed organizational institutions.
Clear differentiation of government sector.	Blurred lines between government and non-government.
Activism and secularism.	Decline of scarcity values and rise of secular humanism.

Gross, B. M. Spacetime and Postindustrial Society, in Spatial Dimensions of Developmental Administration, ed. J. Heapher; Durham, N.C., Duke Univ. Press, 1971. p. 226

These and other changes indicated by Gross would occur at varying rates and in varying forms, but insofar as they constitute probable features in the structure of American society, they suggest some future developments in governmental role and function.

Professionalization of the labor force

The movement of manpower from goods production to service production is already evident both in the public sector (tremendous growth in number of public employees at all levels) and in the private sector—where there has been growth of health, legal, educational, accounting and computational, and consulting professions, and in transportation, communication, finance, insurance, real estate, and general service occupations. Over the past two decades, white collar jobs grew at a rate more than three times as fast as blue collar jobs. Farm labor has greatly decreased; factory labor is seriously affected by automation and by export of production.

Governmental policies, in order to ensure the distribution of employment, its application to "public" goods, such as environmental control, health services and the like, and to "ensure the domestic tranquility" in a world where change is rapid, must be addressed seriously to manpower problems. A Delphi study sponsored by the U.S. Department of

Labor in 1970 and involving 62 manpower experts found, according to Nanus, that:

- The percentage of the Federal budget devoted to manpower problems will greatly increase.
- Within 10-20 years the most important manpower problems will shift from the present policy emphasis on helping the disadvantaged to find jobs, reducing unemployment and equalizing opportunity, to a future policy emphasis on maximizing job satisfaction and improving the system that creates the poor.
- Employment counseling will greatly increase, supplemented by programs of skills development and retraining.

The future may see much greater mobility in occupations and an increase in the "recycling" of manpower to meet changing opportunity and to provide for personal growth. This would require greatly expanded employment and counseling services, with a redirection of educational systems to provide continuing and iterative training opportunities. They would cover all levels of proficiency, including retarded and otherwise handicapped persons.

Governmental manpower-forecasting services geared to the total world of work and its changes will be a necessity, and this could include the survey of low-skill jobs appropriate for mentally retarded workers. Such jobs would be of greatly increased variety, especially in service areas.

All of this implies an expanding role of government in the field of manpower, including

- Government subsidies for educational achievement in low-income and low-productivity families.
- Widespread government support for child day care centers.
- National medical insurance and coverage, prenatal through old age.
- Low-cost housing for the poor.
- More decentralized, government-supported education programs (neighborhood classes and in-home instruction) which can be greatly facilitated by new communications technology.
- Federal attention to the problems of school districts with high population and low tax base.

The controversy which such movements will entail will center in the issues of cost-effectiveness of manpower development against growth in bureaucratic controls. The outcome is contingent on sufficient decentralization to make government responsive to citizens' demands without merely adding to the layers of bureaucracy.

Cybernation and Computerization

The revolution of information management and its use in automation and communication is well under way. All the futurists have emphasized this and regard it as one of the key elements in the design of the future. The potential impact of computerization in developing and maintaining information systems is massive for two reasons: (a) all other resources are dependent on information systems for evaluation and utilization, and (b) information is the only resource not depleted through usage. Use of information location and dispersal systems can narrow the intervals between discovery and application. Furthermore, information sharing can be used to construct prototypes and avoid the needless hardship and cost of experience via simulation. This is consistent also with an emphasis on the enhancement of long-range manpower forecasting.

It seems fairly certain that the functioning of the government bureaucracies at Federal and State levels could be greatly improved through increased utilization of computer science geared to effective systems management. A prerequisite would be a definition of the role or role combinations the Federal and State establishments will assume: developer, manager, sponsor, or procurer of management information systems. In addition, specification of what kinds of information, in what form, for what purpose, will have to be more systematically addressed.

Quality control over Federal and State human services dollars will have to be accomplished through more precise evaluation of variables in both the service process and in the outcomes for those receiving service. The de-

velopment of this capability seems both critical and within reach if made a Federal priority.

"A data base which is oriented toward program and treatment evaluation is also a potentially valuable research tool. It is conceivable that, with an information base which is adequate for demonstrating the benefits of investments in human services . . . it may be possible to make a case for allocation of resources very much more in the direction of human services."

Adelson

Complex, mixed organizational constellations

Assuming resource sufficiency, as the futurists do, one of the major service problems is access to services.

". . . The needs which these services are intended to meet are not organized in the same way that the services are . . ."

Adelson

The organization of human service delivery systems should guarantee access on an individual basis. The problem is to establish an intermediary mechanism for bringing together the public and private producers of service, the agencies providing funds, and the individual consumers who need unique patterns of service. Linvill introduces the concept of "brokerage" as the mechanism necessary to guarantee effective access. The concept is sufficiently important and novel to justify inclusion here of Linvill's summary of the key elements of the proposal:

Integrating Human Service Delivery

- Substantial resources are available to deliver human services; both public sector budgets and private budgets seen adequate in many cases.
- There is a wide variety of producers of human services; however, the individual servers are specialized and tend to be isolated from deliverers of other services.
- There is a very wide variety among the needs of various consumers of human services. A high value is attached by each individual to finding services which are tailored to meet his needs.
- There is a wide variety of support institutions, many of them in the public sector; however, there is a substantial lack of flexibility in funding or eligibility guidelines.

• The basic or underlying problem appears to be one of providing *access* to services so that an individual can receive the set of services which meet his particular needs.

• Though there are many servers, many sources of support, and apparently adequate overall funding, an individual still cannot get his needs for human services met, particularly if he is young, old, physically or mentally handicapped, or unemployed.

• The idea of centralized governmental control to deliver services needed by the individual is repugnant; moreover, it could not possibly provide the flexibility needed.

• We propose to improve access to services by providing the support services of information, scheduling, accounting, and transportation facilitation through a network of community brokers.

• The broker presents the individual consumer with a set of alternative plans in response to a given problem situation. The consumer chooses that set of services which he prefers. *Thus, the community broker facilitates a market in human services.*

• The flexibility to meet the needs of individual consumers and the adaptability of the overall system to meet the changing needs of the community servers, supporters, and consumers, is provided by the market mechanism.

• The network of community brokers must occupy a neutral position with respect to the producers and supporters of service in both the public sector and the private sector. Accordingly, we propose that the network of community brokers and their activities be a private sector venture, possibly a community cooperative, which would receive its operating funds from the cost savings generated by the community broker.

• The institutional brokerage among the community of consumers, the producers of services, the supporters of services, and the network of community brokers (possibly as community cooperatives) will be assured only if the institutional brokerage is provided by an entity having a neutral position with respect to all of the elements. Accordingly, we propose a company in the private sector called an Institutional Brokerage Company which will serve the function of institutional brokerage.

• The Institutional Brokerage Company will do institutional brokerage among the institutions related to human service delivery in each community. It will develop the technological backup for information systems, for scheduling systems, and for accounting systems; and if necessary, it will develop the capability for transportation facilitation, even to providing vehicles. The Institutional Brokerage Company will launch individual community cooperatives, will train the individual community brokers, and will provide the backup support necessary for launching new community cooperatives.

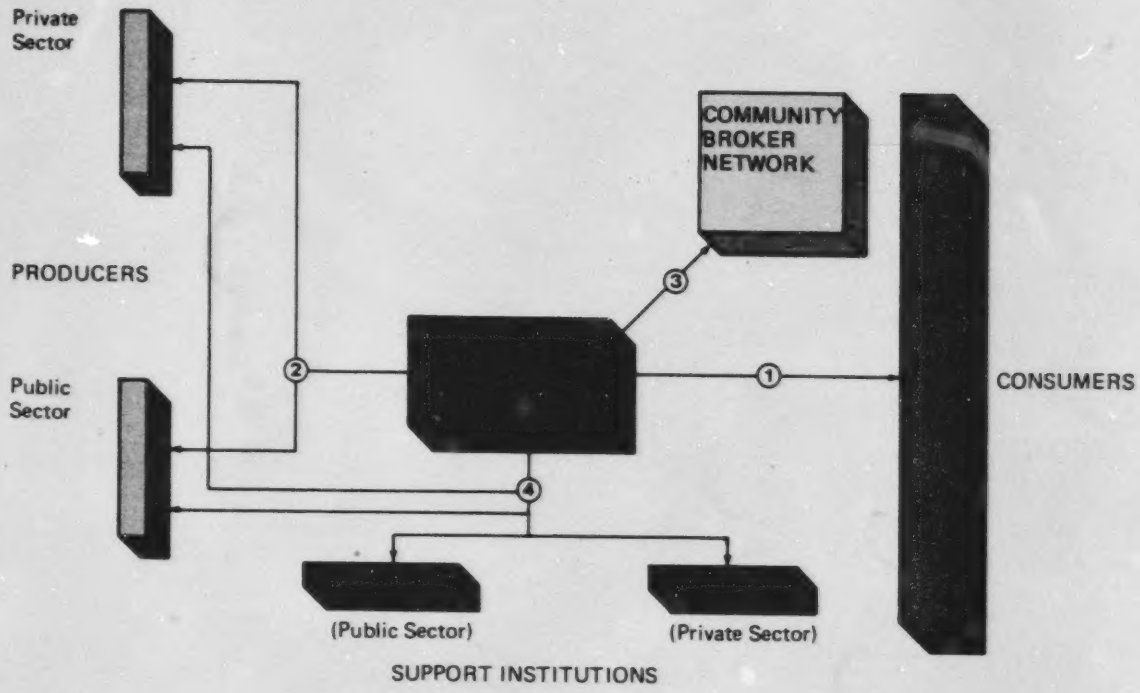
• The individual community cooperative in its steady state operation becomes the institutional representative of a community of consumers of individual services.

• The economic viability of both the institutional brokerage company and of the individual community cooperative is based on their ability to be paid for improving the quality of services accessible to individual consumers. Economic independence and viability are necessary prerequisites for their effective neutrality to deal with many public and private institutions.

Blurred line between government and non-government

A system of brokerage-facilitated human service delivery illustrates one way in which the governmental and non-governmental lines become blurred in complex system organization. It serves a similar purpose to the technical advisory bodies and consumer councils now increasingly used in governmental decision-making and information flow—that purpose being to mitigate the impersonality in operations of bureaucratic agency structures.

The Institutional Broker Facilitates Relations Among Institutions to Improve Service Delivery System



Further changes in methods and patterns of decision analysis and decision-making are likely to occur. On the precedent of the Environmental Impact Reports required for Federally funded construction, it may not be long before "Social Impact Reports" will become a requirement for proposed major programs of any kind:

"As the art of social impact analysis develops, the diverse impacts of given steps on various sub-populations or sub-regions could be the subject of systematic governmental and public attention . . . Decisions taken at any level will be increasingly well analyzed for impacts at all other levels . . ."

Adelson

A procedure for cross-impact analysis of any number of program elements has been developed by J. Kane, and applied by Linstone to mental retardation futures. By this model, the various aspects of mental retardataion programs can be seen in terms of their favorable or unfavorable impact on one another in terms of their relative probabilities. From baseline values effects can then be calculated in relation to external variables. Thus, the effect of political climates of various sorts on such PCMR goals as reduction of incidence of biomedical or socioeconomic retardataion, improved human service delivery, or public acceptance and citizens rights may be forecast.

The Federal Government might involve the private sector in the planning of new programs by getting its input for a Social Impact Statement.

Decline of scarcity values and the rise of secular humanism

The futurists were essentially of one mind with regard to the question of overall scarcity of resources.

"The situation of the future, we believe, is not scarcity-dominated, but is sufficiency-dominated."

Linvill

A prediction that it will take about a decade for "the possibilities of relative material abundance for many more people to be perceived" suggests that:

"The possibilities of greater attention and allocation of resources to such social programs as MR are, therefore, much better than our current crises may lead us to anticipate."

McHale

Among the effects of the decline of scarcity values and of a general scarcity orientation to life and work will be an upgrading of expectations about the quality of life, and most likely a more generous outlook regarding an equitable "fair share" for retarded citizens.

The futurists are not inclined to regard the current situation as less than a real crisis, but see it as largely a political crisis relating to the distribution and utilization of particular resources such as fossil fuels, on which we have heavily built our economy and life style. They recognize that it will take time, effort and some diplomatic forbearance to resolve current problems. They recognize also that a basic sufficiency does not mean unlimited abundance and that carefully planned, cost-effective programs will still be in competition for allocation of resources. The central point, however, is that the optimistic anticipation of sufficiency can have a quite different impact on short-range decisions than would a pessimistic expectation of an economy of scarcity for the foreseeable future.

Expectations of long-run sufficiency have at least two major implications for the Federal role. First, they should facilitate experimentation in patterns of service delivery so that a variety of prototypes will emerge to meet changing needs and improved conditions. Adequate support with which to build these prototypes is needed, however.

"... The kind of shoestring programs that have characterized many [service development] attempts up to now may be more dangerous than helpful. It is probably wise to invest quite a lot in the conceptualization of comprehensive approaches and their implementation on a pilot basis."

Adelson

A related point is that in an atmosphere of relative sufficiency, the value structure permits a much higher risk-taking threshold, for example, in prototype building in anticipation of increased resource availability.

The second Federal implication is that more emphasis can be placed on establishing long-term priorities. In contrast, an expectation of long-term scarcity forces emphasis on dealing with immediate symptoms of human problems on a crisis-to-crisis basis, rather than with the more fundamental conditions from which human problems derive.

Conclusion

No projection of the future is a certainty. There is an element of faith underlying every step taken in any direction from the present moment. Human beings are accustomed, however, to act on the basis of less than certain expectations. Evidences of danger can be early warning signals to change course; evidences of positive benefit can be a spur to action that will make the benefit real.

Contemporary society has many warning signals in view, which we tend to discount when the danger lies some way ahead. "Future discounting" is as great a danger as wishful thinking, because inaction can bring disaster that could have been avoided. The tendency to look through the wrong end of the telescope, making the future danger appear small, may also have its counterpart in magnifying the problems ahead until they appear insurmountable and we simply give up in despair. Steep hills have a way of flattening out as we mount the slope.

We have mounted the slope toward resolution of the problem of mental retardataion. But there are steeper grades ahead which

may appear discouraging, since they involve problems of human organization far greater in scope than the retardation which is one of the byproducts.

We dare not discount the future either in terms of its portents of danger or of its indications of better things to come.

". . . There may not be all the time in the world left to deal effectively and humanely with MR. Despite the benign sound of some of the prospects generated earlier in this paper, there is some likelihood that time will run out on people's willingness to support mentally retarded people and programs for dealing with mental retardation.

Adelson

In order to deal with the long-term probabilities, there is need to focus on short-term developments that will sustain positive support under currently adverse circumstances. These short-term developments include:

- Demonstration of the economic potential of retarded persons that can be made available through investment in mental retardataion programs.

- The designing and sustaining of a process of active, systematic, informed attention to mental retardataion as a problem *to be* solved.

Our focus on these and other critical short-term developments is not only to ward off the possible effects of a negative future. We must also push the limits of the present to help shape the positive kind of long-run future for mentally retarded people that we know is possible.

The President's Committee on Mental Retardation is convinced that a vigorous, forward-reaching continuation of effort can achieve goals that are feasible, humanitarian and in keeping with our best national traditions and ideals. In the following chapters, the Committee states seven major goals relating to mental retardataion and a number of objectives which constitute essential means to their realization. The Committee proposes to the President and to the country a series of steps for reaching those objectives over the next 25 years.

The following "futurists" were cited in this chapter:

Marvin Adelson, Ph.D., Professor, School of Architecture and Urban Planning, UCLA.

Roderic Gorney, M.D., Associate Professor of Psychiatry; Director, Program on Psychosocial Adaptation and the Future, School of Medicine, UCLA.

Harold A. Linstone, Ph.D., Professor and Director, Futures Research Institute, Portland State University.

William K. Linvill, Sc.D., Chairman, Department of Engineering-Economic Systems, School of Engineering, Stanford University.

John McHale, Ph.D., Director, Center for Integrative Studies, University of New York at Binghamton.

Burt Nanus, D.B.A., Director, Center for Futures Research, University of Southern California.

Stanley C. Plog, Ph.D., President, Plog Research, Inc.

Rod Mulligan and Sara Costeau

They told her they wanted to be married. It took nerve for them to say these words to Sara's counselor from the community agency. They wanted this to happen, but underneath they were fearful. Would this be the right thing to do? What would others think? Would the staff approve? Fortunately, the community agency in this east coast city was prepared to help people like Rod and Sara with questions like these.

Rod and Sara had lived most of their childhood and adolescent years at the same institution. There had been little contact between them. Institutional policies required strict segregation of the sexes. Only at special parties and activities were young men and women allowed to get together, and these occasions were monitored by staff. It never remotely occurred to them that they would ever consider marrying each other.

In 1973, each moved to a different supervised apartment in the same city. They attended the same vocational training center until Rod took a job washing pots and pans in a bakery and Sara began work with a cleaning crew in a bank. During the winter weekends of '74, a friendship developed between Rod and Sara. They began meeting at the bus depot. They sat and talked together. When they were hungry they bought hot dogs and Cokes. Their companionship contained a

"Their companionship contained a mixture of longing, tenderness, fear, argument, and pain."

mixture of longing, tenderness, fear, argument, and pain.

The community agency offered them a chance to attend a group session for those thinking about marriage. They accepted. The group met weekly for 3 months.

Five couples met with two group leaders. At first, the group talked about how two people get to know one another. Each couple was encouraged to describe the things they said and did together. As the couples shared experiences and "role-played" their associations, it became clear that Rod and Sara were communicating fairly well. However, the leaders felt there were areas where they had special needs.

"Rod would tease Sara about her plumpness. He expected her to laugh. She didn't. Sara retaliated by saying she was looking for another boyfriend. Then, Rod felt pain. They needed to become sensitive to what hurt the other."

One of the group leaders pointed out another problem:

"Rod and Sara had never had a chance to be close to other models of courtship—or even models of the family for that matter. The institution simply has no such models available. For this reason, we planned for Rod and Sara to double date with other staff members in their early twenties. It was amazing how hungry they were to copy the specific attitudes and actions involved in dating."

A dance instructor taught the group a few basic ballroom dance steps in preparation for a Christmas dance. Rod and Sara took delight in moving their feet according to a set pattern. Rod felt proud that he could provide the leadership for such steps.

After Christmas, a team of two people from the local planned parenthood unit worked with the group on sexual development, intercourse and childbirth. These included the showing of love and tenderness for the partner during intercourse, and the utilization of various birth control devices.

Rod and Sara felt uncomfortable during these sessions. After many years in an institution of the old type, where sex was a taboo subject, it was hard for them to talk about such acts without feeling confusion and guilt. Nevertheless, their companionship was affectionate and mutually supportive.

Because of the risks and their mutual choice against having children, Sara chose to be fitted with an intrauterine device.

The final phase of the group meetings had to do with basic agreements two people need to make in a marriage partnership. Here, Rod and Sara broke many family stereotypes. Rod liked cooking. Sara did not. Rod would take leadership in the kitchen. Both would work together cleaning their apartment. Each would be responsible for his or her own funds. Each would pay half the rent, utilities and groceries. Each would set up separate personal savings accounts.

They asked if they could continue calling one of the counselors assigned to them if disagreements arose that they could not solve. They had already been doing this, and they felt the need to continue such an arrangement.

Rod and Sara are now in contact with a clergyman who is helping them with plans for a wedding ceremony. They have begun to look for an apartment. However, they have not yet come to the point of setting a wedding date. The counselors remain available to help them with any decisions they make. Sara's counselor sized up the present situation by stating, "All of us, with our weaknesses and our strengths, finally choose to make the jump or we don't. If Rod and Sara do get married, they will need the support of friends and the community agency for a long time. At any rate, they seem to have found more in their life together than sitting in the bus depot."

Chapter 3

Full Citizenship and Legal Rights

"... the retarded person has the same rights as all other citizens ..."

Mentally retarded people have in the past suffered extensive discrimination in the exercise of constitutional rights. During the past 10 years, significant advancements have been made in defining the legal status of the mentally disabled person, in clarifying and establishing procedures of due process, and in implementing the retarded person's equality under the law. This represents only a beginning, however. The retarded person still suffers from the persistence of past inequities and the discriminatory restriction of rights.

The basic premises on which the following discussion and recommendations rest are these:

- Retarded people have the same rights, legal and constitutional, as every other United States citizen, including the rights of due process and equal protection of the laws.
- Retarded people can be more independent and can function more competently and responsibly than is commonly believed —mental retardation and incompetency are not synonymous.
- Full citizenship exercised by a retarded person in a community setting is possible and is in the public interest.

On the basis of these assumptions, which have been increasingly recognized during the last decade in the legislatures, the courts and in society in general, a number of specific rights deserve special attention in order to remedy the effects of past discrimination. These include, but are not limited to the following:

- The right of equal access to quality health care, both medical and dental, and social services adapted to need;
- The right to residential programs and other supportive services in settings most conducive to development and independence;
- The right to equal educational opportunity adapted to need;
- The right to equal employment opportunity and economic security;
- The right to marry and bear children;
- The right of due process and equal protection of the law in the criminal justice system;
- The right to vote.

Prior to discussion of these rights, two key terms need to be clarified: *competence and consent.*

Every mentally retarded person, as every other citizen, is presumed to be competent. Only where there has been a full due process hearing can anyone's rights be restricted on the basis of incompetence. This restriction of rights should be limited to the specific problems which the individual has been shown to be unable to handle and which involve possible harm to himself or others. There should be a recogni-

tion of gradations and separability of competences, e.g., the individual who is unable to make a formal contract involving sums of money should not be deprived of all right to make money transactions, nor lose all civil rights because of this inability. The idea that, because a person is incompetent to do one thing, he is therefore incompetent to do all things is absurd, and contrary to the facts of everyday life. Legal incompetency, which is generally taken to mean an inability of the person to manage his own affairs, should be based on facts to be determined for a specifiable set of circumstances, at an appropriately conducted hearing, and established in a specific legal judgment. Incompetency, once a judgment has been made, should be subject to automatic periodic review and rights restored when evidence of the previous impediment is no longer found to exist.

The concept of consent directly relates to the presumption of competence of each mentally retarded individual in the absence of a legal finding to the contrary. Consent requires an informed decision by an individual. A mentally retarded person should be presumed able to make informed decisions when presented with pertinent facts and in language he understands. However, the more serious the decision and the more there is a question of an individual's ability to understand and weigh the facts, and thus give informed consent, the more there is a need for review of the decision by a personal representative or advocate recognized as competent to consult with the retarded person and to speak in his behalf. (See Humane Services, Chapter 6, Objective III)

The concepts of competence and consent are not static. The movement to protect the legal rights of the mentally retarded citizen is based on a challenge to the traditional view of the retarded person as an individual with little or no ability to learn, to develop or to function within the framework of citizenship. As scientific knowledge and direct experience with the accomplishments of retarded people have increased, so our perception of the limitations of ability has been altered. The potential for growth and development of the retarded citizen, given appropriate opportunities to learn and to use his learning under supportive conditions, has become an emerging concept. The conditions of consent must not be locked into inflexible definitions, but must allow for future modification in the light of expanding knowledge and educational skill.

The following statements represent the President's Committee's views on rights of retarded persons and the conditions governing their possible limitation.

The right to equal access to quality health and social services adapted to need

• *The right to be free from the arbitrary denial of lifesaving medical services.* This right is premised on a recognition of the universal value of human life and the recognition that mentally retarded persons must be allowed equal access to medical services to preserve their lives. Such a right rules out any practice which would "allow" a retarded person to die based upon a judgment that the quality of life of a retarded person is less than that of other citizens, or any routine policies or guidelines predetermining the withdrawal

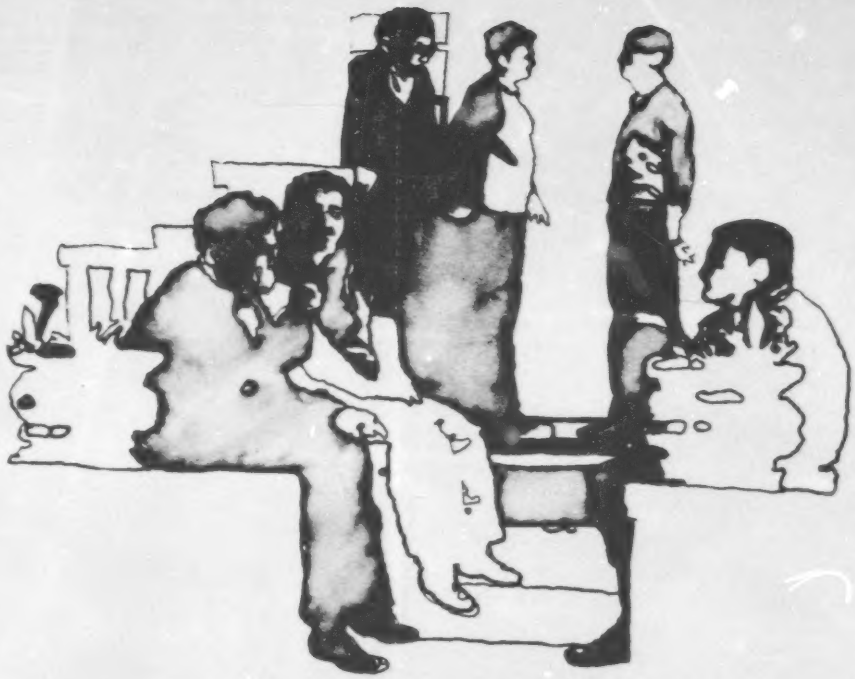
of life support from impaired newborn babies based on predicted development potential.

• *The right to medical and medically related services on an equal basis with other citizens.* This right includes all medical, dental, and surgical treatments available, as well as occupational and physical therapy, speech and language services, etc., as they may be indicated.

• *The right to be protected from unnecessary and experimental research procedures.* Such a right prevents mentally retarded individuals from being subjects of medical or behavioral experimentation, unless the individual or his legal representative has given an informed consent, consistent with regulations promulgated under law governing the use of human subjects in research.

• *The right to health services necessary to prevent or control mental retardation.* The right includes access to nutritional and dietary programs, maternal care, and beneficial medication. It includes also the right to be free of unnecessary and debilitating drugs employed solely for behavioral restraint.

• *The right to have access to all available social services which facilitate the retarded person's adjustment to society or which facilitate his development.* This right precludes an agency from denying services solely on the basis of mental retardation.



The right to residential programs and other services in the setting most conducive to development and independence

• *The right of equal access to the variety of housing opportunities available in a community.* This right includes the normally exercised choices of where one lives and with whom one lives. Such a right prohibits restrictive zoning on the basis of personal human characteristics, including mental retardation.

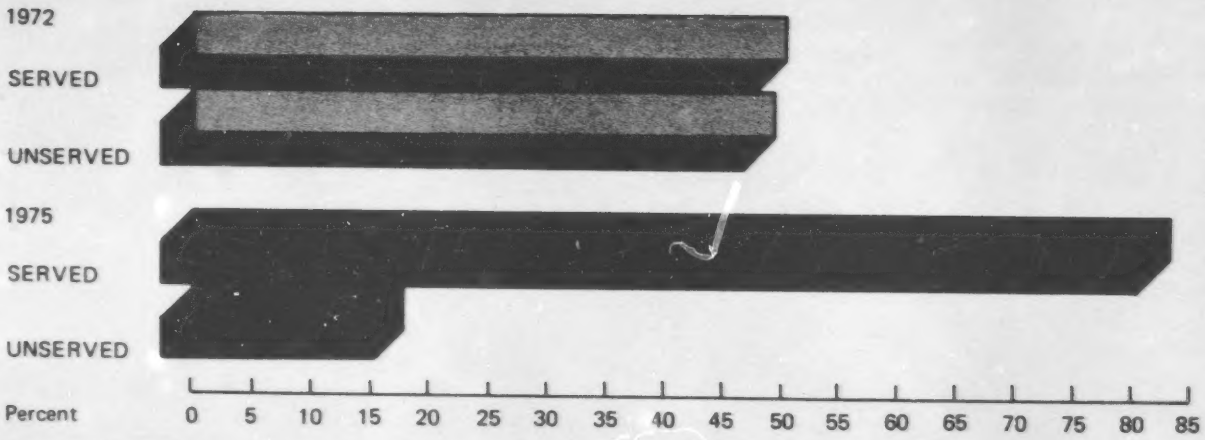
• *The right to live and to receive services under the least restrictive conditions.* This right guarantees that the retarded person have the opportunity to lead as normal a life as possible. The services and residential programs must be provided in the community or as a related extension of community-based programs.

• *The right to be free from arbitrary commitment to a specific residence solely on the basis of mental retardation.* Involuntary admission to a restrictive residential situation should be only in the interest of public or personal safety, on the basis of full judicial proceeding, and subject to review.

• *The right to be free from custodial programs offering little or no developmental or supportive services.* Such a right should prevent continuation in warehouse-type facilities as well as placement therein. The retarded individual has the right to immediate relief from such institutionalization and transfer into a home providing access to needed programs and appropriate treatments in the least restrictive and socially most beneficial situation.

• *The right to appropriate care, treatment and habilitation based on an individualized program.* This right is applicable to all retarded persons who are within

Mentally Retarded Children Served By Public Schools 1972 and 1975



Source: U.S. Office of Education/Bureau of Education for the Handicapped.

comprehensive institutions or in the local community and this right is also applicable during the transition period when officials are taking affirmative steps to develop appropriate community programs.

The right to equal educational opportunity

This right implies the opportunity for maximum development of individual capabilities and includes the recognition of the following concepts:

• *Zero reject public education.* No retarded person, regardless of the degree of mental retardation, should be excluded from a free public education.

• *Individualized programs.* Equal educational opportunity requires an individualized program suited to the needs and designed to develop the capabilities of each person to the fullest extent possible.

• *Most constructive program and setting.* Mentally retarded persons should be educated under circumstances that are the most conducive to normal learning and social adaptation. Of various alternative educational programs, they should receive education in the least restrictive and most normal environment which can be provided, with due regard to cultural and ethnic diversity as well as to individual need.

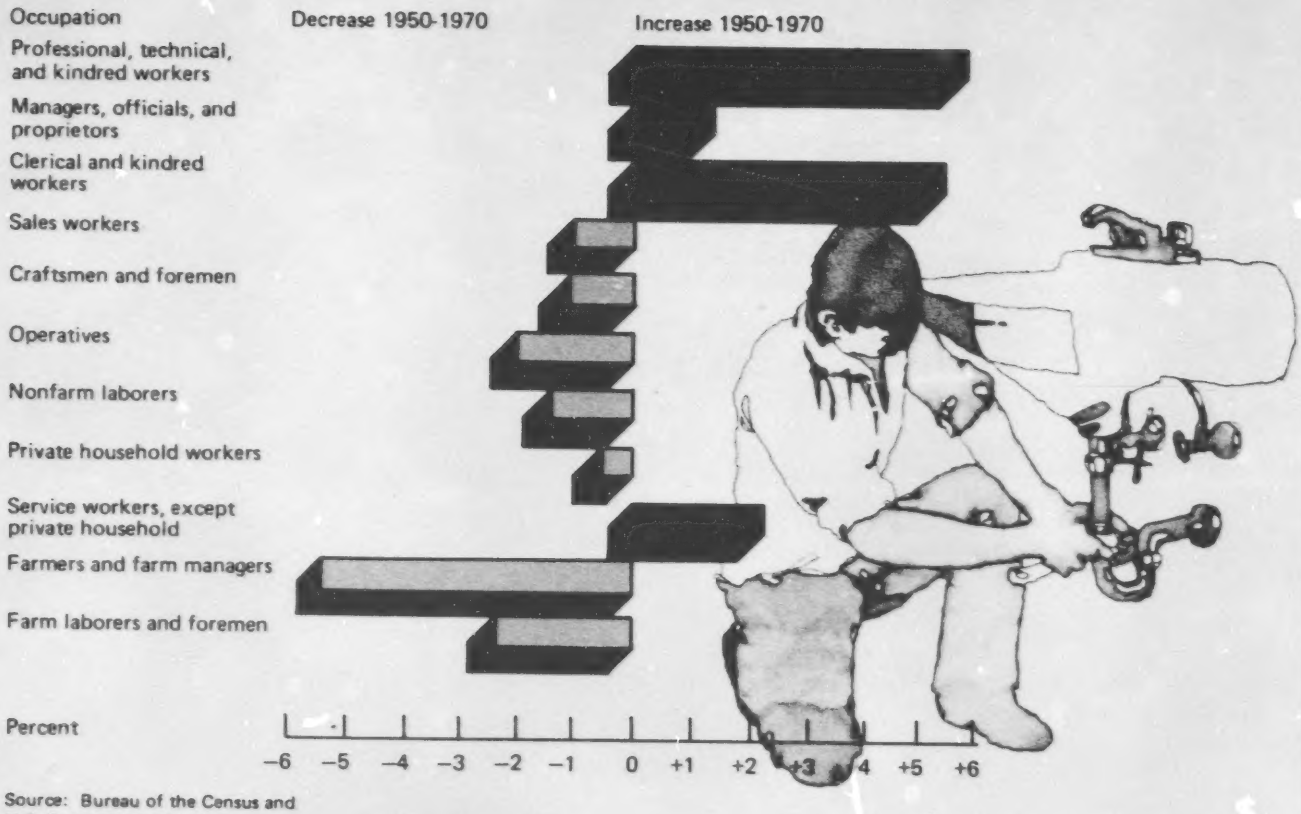
• *Due process protection.* Every special educational placement, denial of placement, or transfer must be preceded by constitutionally adequate notice and hearing procedures.

• *Periodic review.* Any placement in a special education setting must be reviewed periodically to determine whether or not the program is accomplishing the specific objectives which were outlined in the individualized program plan.

• *Centralized responsibility.* This concept allocates to a single agency the duty to insure that educational programs are provided to *all* mentally retarded persons regardless of their present living situation.

• *Extended educational age, compensatory and continuing education.* Because of the learning characteristics related to mental retardation, eligibility for public educational services should have no minimum or maximum age limits. Because many retarded persons have in their earlier years been denied educational opportunity, compensatory educational services should be available. As long-term policy, adult educational opportunities, including appropriate programs provided by higher education, should be available for citizens with mental limitations.

Occupation of Employed Persons: 1950 and 1970



Source: Bureau of the Census and U.S. Department of Labor.

The right to equal employment opportunity

• *The right of equal access to job opportunities.* The mentally retarded citizen should have access to any job in the market that he or she can perform. Such a right condemns discriminatory testing and denial of jobs or promotions on the basis of factors irrelevant to performance.

• *The right of equal access to job training.* Such a right requires vocational rehabilitation programs of wide variety, including training in sheltered workshops and in other protected settings as well as on-the-job, where the individual can acquire the skills necessary to compete in the job market or to work under whatever protected or limited conditions the degree of his disability requires.

• *The right to work in the setting in which the individual can be most productive.* For some this might be under protected or sheltered conditions or on a part-time basis, or with reduced output expectancy.

• *The right to an adequate income.* This implies the right of those persons who are not able to compete successfully in the job market or to produce at minimum economic levels to be included in any system of minimum guaranteed income.

• *The right to be free from architectural or orientational barriers in buildings and in transportation systems. Such*

freedom facilitates the realization of equal access to all employment opportunities and other areas of social activity.

The right to marry and to bear children

- *The right to be free from restrictions on the sanction to marry.* This right condemns blanket invalidation of a marriage because one or both of the partners happens to be retarded.

- *The right to be free from involuntary sterilization.* Such a right outlaws the practice of involuntary sterilization of retarded persons. It also condemns the use of coercion against any retarded individual in order to obtain a "voluntary" consent necessary for a sterilization. It invalidates laws requiring sterilization as a condition of marriage.

- *The right of equal access to voluntary sterilization.* Many retarded individuals *do* have the ability to make a competent decision to undergo sterilization. These individuals should not be denied the sterilization because of their retardation. In case the individual is legally incompetent or sufficiently impaired to be unable to make an informed decision in his own behalf, ample legal, social, ethical, and professional safeguards should be rigorously imposed to insure that the best interest of the retarded individual remains paramount in the decision-making process.

- *The right to procreate, nurture, and rear children.* This right presumes the competency of retarded individuals to raise their children as would any other citizen in the absence of a specific juridical finding to the contrary.

The right to equal protection in the criminal justice system

- *The right to have qualified counsel* from the time of arrest.

- *The rights of retarded persons can be protected only if police and other law enforcement officials can recognize retardation,* or at least can recognize the need for an expert evaluation in cases of doubt.

- *Lawyers practicing in the criminal justice process should have sufficient background* in mental retardation to provide effective counsel to mentally retarded clients.

- *The right to have evidence presented as to the diminished capacity of the accused person.* This right would allow the court system to find different levels of responsibility depending on the individual facts in each case (not simply a finding relative to ability to distinguish right from wrong but ability to understand the charges brought against the person and the evidence on which he is tried).

- *The right to be held responsible* for acts that are within his choice, control, and comprehension.

- *The right to rehabilitation.* Such a right within the criminal justice system should mean that the convicted retarded person receives decent living conditions

and individualized programs designed to meet specific needs for rehabilitation.

The right to vote

- *The right to exercise the voting franchise* should not be lightly restricted, since it is the foundation of democratic citizenship. This right condemns blanket restrictions on the right of retarded persons to vote. It recognizes the ability of many retarded persons to participate fully in the decision-making process of our government by casting a vote for the candidate or issue of their choice.

- *The right of access to the polls.* This right includes access to voting places for those in institutions as well as for those living in the community. Such a right would also imply the availability of resources facilitating registration as an eligible voter.

- *The right to be free from undue influence* or coercion in the exercise of the voting privilege.

- *The right to instruction* in the fundamentals of civic responsibility and the exercise of the vote.

There are many other specific rights which could be discussed here, such as the right to licensure on a basis of qualification, the right of testimentary disposition of property, the right of mobility in the public ways of the community, and many more. Failure to mention any such right here does not mean it is of any less validity or of less concern to the President's Committee. All such rights are subsumed under the general declaration that the retarded person has the same rights as all other citizens, including the right of due process in the limitation or abrogation of any right and of equal protection of the laws in the exercise or enjoyment of any right.

The counterpart of right is responsibility. They are the two sides of the coin of citizenship. Consequently, insofar as a person with some degree of retardation is held to be competent in any aspect of life, he may be held accountable for his actions in that aspect of life. A retarded person who marries, for example, is expected to exercise responsibility in maintenance of the marriage contract. He may, however, need assistance in doing so and training in the domestic and social skills necessary to sustain a marriage relationship. Inability to exercise appropriate responsibility is, in essence, the basis on which rights may be limited by judicial action, but also the basis on which training and support are essential.

Based on the foregoing assertions about the nature of rights and their implications for mentally retarded persons as citizens, the President's Committee states the following goal:

The attainment of citizenship status, in law and in fact, for all mentally retarded individuals in the United States, exercised to the fullest degree possible under the conditions of disability.

The realization of this goal requires a degree of public acceptance as yet unattained; this will be considered in a later chapter. It requires also a foundation in law and equity for 1) the assurance of maximum freedom of the retarded person to exercise legal and constitutional rights, 2) the assurance of the maximum independence of the retarded person in the responsible management of his own life, and 3) the assurance of maximum access to a free and open community. These requirements may be fostered by achievement of the following objectives in the administration of supportive and protective law.

Objective I: *The assurance of maximum freedom to exercise legal and constitutional rights and responsibilities.*

The enumeration of rights and their implications is of little value if they are systematically disregarded as they have so often been in the past. This has been in part because of confusions and inconsistencies in the law, partly because of ignorance, partly because legislation has often wrongfully violated fundamental rights of retarded persons. Basic legal protection must be applied and enforced with vigor.

- A duly selected body working in concert with public and private agencies should *develop at an early date a legislative guide and information-sharing system* to be used by the States to develop statutes to protect the constitutional rights and facilitate full citizenship of mentally retarded and other handicapped persons.

- *All States that have not already done so should institute a careful review and revision of their statutes and legal practices* relating to mentally retarded and other handicapped persons, to ensure conformity with constitutional guarantees of equal rights, due process, and equal protection of the laws.

- *A nation-wide system of "public" legal advocacy services* specializing in the protection of rights should be available to mentally retarded and otherwise handicapped persons. Branches of this system should be established in all States.

Such service, which, in part, has been performed by the American Civil Liberties Union, in part by the development of legal advocacy services in the courts, could well be developed on a generic basis. Various forms of development can be envisioned, as a purely State and local function, or with a national point of reference. From the standpoint of this report, the important point is that such services be available to assist mentally retarded persons in the technicalities of obtaining fair and proper hearing in legal procedures.

- *Offices of special appeal*, with final recourse to the courts, should be available in each State to protect the rights of the retarded and other handicapped individuals as well as those of others. The offices should be established as commissions or public corporations separated from the regular governmental systems, with authority to act independently on behalf of handicapped citizens.

Such agencies have been established in some States to handle complaints of violation of equal employment opportunity laws or other matters of individual right. The extension of such offices or agencies to serve as the recipient of complaints by retarded persons and as the expediters of conciliation could avoid costly civil suits and other court procedures. As in advocacy above, there are various conceivable forms which such protective services could take. One important avenue for establishing such services was opened in October, 1975, with passage of the Developmentally Disabled Assistance and Bill of Rights Act; Section 113 of this Act conditions receipt of certain Federal funds on a State having an independent system to protect and advocate the rights of persons with developmental disabilities.

- *Statutes and court procedures bearing on competency* should be clarified and revised a) to recognize gradations of competence, b) to recognize that areas of competency may be quite varied and therefore

should be separable in law, c) to assure full and explicit due process safeguards on any and all areas of competency and that the scope of any judgment of incompetence is made fully explicit, and d) to ensure that restrictions of competency be limited to a specific period of time or subject to periodic review.

• *The LEAA program of the Department of Justice* should concern itself with a variety of matters affecting mentally retarded persons in both the civil and criminal justice systems. These would include the clarification of procedural matters; pre-service and in-service training of lawyers and law enforcement, court, juvenile justice, and criminal justice personnel in the nature of retardation, the legal and constitutional rights of handicapped persons, and procedures relating to retarded individuals; and the provision of funds for research and study of these matters.

Means to this end would be the development of an information center where model curricular and case materials could be disseminated; together with symposia and conferences to foster information and interest.

• *All professional persons who work with mentally retarded individuals should be trained to recognize issues of human right*, including but going beyond legal issues.

• *Educators, social workers, and other counselors should be trained to impart to mentally retarded persons an understanding* of their rights and concomitant responsibilities in a more open society.

• *Establishment of programs* 1) *to prevent delinquency* in retarded persons at risk, 2) *to divert the handling* of retarded offenders from the regular criminal courts to other procedures, and 3) *to provide corrective rehabilitation* of retarded juvenile and adult offenders.

The magnitude of this problem in its relationship to poverty, racial and ethnic problems and other social ills is so great that it warrants serious and immediate attention on a large scale. Approach to the problem must ultimately be through the root causes, not through the treatment of overt manifestations alone.

• Every effort should be made to consider and *resolve issues in regard to maintenance of and access to records* of handicapped and other persons. The issues revolve around the rights of privacy, personal access, confidentiality of communications, "need to know," and appear to involve issues of conflict of rights.

The critical issues involve the necessity of maintaining a balance between the rights of privacy and confidentiality and the "need to know" on the part of persons responsible for the interests of the handicapped individual and his case management. The usual procedures of signed release permitting access are complicated by the degree to which the retardation may limit understanding of the issues and their implications. In the absence of a legal guardian the authorization authority must be fully clarified. Certainly any use of personal records for statistical research or epidemiological purposes must safeguard personal identification.

Objective II: *The assurance of maximum independence of retarded citizens.*

The route to full citizenship lies in the maximum participation in the functions of normal living. This requires maximum development and use of the individual's resources, with whatever supplemental supports are necessary to make them socially functional. Such development reduces physical, social, economic, and residential dependency. The content of a humane system of protective, developmental, and supportive services is defined in Chapter 1 and discussed in Chapter 6. The following are recommended legal means to establish and sustain such a system.

• *The development of a compendium handbook*, subject to annual revision, codifying statutory provisions of the States and the Federal Government concerning

•• Legal status, competency adjudication, and guardianship (both of person and property) for mentally retarded persons.

•• Protective, developmental and supportive services for mentally retarded persons.

• Development by progressive steps of a system which will *guarantee fully adequate economic security and independence* to all people, including mentally retarded individuals. Such a system should begin with current Federal and State programs and develop over time the following provisions:

•• A guaranteed minimum income adequate to meet the normal costs of daily living.

•• A credit or voucher system, vested in the eligible individual consumer in need, whereby retarded in-

divi[illegible] could acquire necessary spec[illegible] services from a choice of accredited providers (See Humane Services, Chapter 6, Objective I). Nothing in these recommendations exempts service-providing agencies from the application of eligibility standards or from accountability in expenditures as provided by law.

• In any modifications of economic security statutes, HEW and the States should *provide by law and regulation for the recognized privilege of any certified personal representatives*, selected by, or under contract to, a mentally retarded person or his legal guardian, to serve as his agent and to negotiate for services in his behalf.

• The Federal Government should provide *financial assistance to the States to cover costs of transition* of individuals from institutional to community services, and costs of transforming or replacing central institutions for more functional purposes consistent with the needs of retarded citizens.

• *A public corporation or commission should be established in each State to provide guardianship services*, including the certification of persons qualified to serve as personal representative agents (See Chapter 6, Humane Services, Objective III.) This function could be served by the same agency as provided in Objective I, "Offices of special appeal."

• Legislation should be developed by the Congress and the States to *authorize and fund adequate systems of humane services* to develop, support and protect the rights of retarded persons as citizens. (The content and structure of such services are set forth in Chapter 1, Issues, and in Chapter 6, Humane Services).

Objective III: *The assurance of maximum access to a free and open community.*

Traditional treatment of mentally retarded persons automatically restricted their space of free movement, physically and psychologically. The retarded person has frequently been confined to limited physical space, limited activity, limited stimulation, limited association except in depersonalized mass groups of equally retarded persons. Or the retarded individual has been neglected in ways which have deprived him of support in the use of his residual assets for mobility within the community and access to its resources. All those measures of control and conditions of neglect closed the community to the retarded person, denying him the humanizing stimulation of social contact and the personalizing effects of using his own resources, developed to maximum potential for enjoyment of his surroundings. The retarded person as a citizen member of society has a right to free movement within it and the right to assistance in learning his way around and making use of the resources of his environment.

It is recognized that in the past a large proportion of children, identified as mentally retarded during school years, later "disappeared" into the adult community and no longer constituted a part of the identified retarded population. This is sometimes made the basis of an argument that social policies, especially where special education and other services have been provided in childhood, have been liberating rather than restrictive. However, evidence of follow-up studies shows that the majority of the "disappearing" retarded people continue to live under marginal circumstances that are, in fact, extremely limiting to the development of their adult lives.

• *Institutional commitment, nonvoluntary or voluntary, should be prohibited* by law except through due process procedures establishing that it is required to prevent the person from doing harm to himself or others or is otherwise in the individual's best interest, that it is the least restrictive solution available, that the period of commitment is specifically limited and subject to court review, and that the subject is represented by counsel at commitment hearings.

• Public laws should be established and enforced requiring the use of positively assisting *devices to enhance the freedom of movement and safety* of the mentally and physically handicapped in all public buildings, transportation systems, public ways, and publicly financed housing.

• State laws and local ordinances should protect the right of handicapped persons to *appropriate residential arrangements*, free of discriminatory zoning regulations, inappropriate licensing standards and codes. (See Chapter 6, Humane Services, Objective IV.)

Bill and Kathy
Robertson

"They were alert to the possibilities of Down's Syndrome . . . The chances increase with age. . ."

Bill and Kathy Robertson worked many years as foreign correspondents for a syndicated news service. As they approached their middle thirties, ... plane schedules and the deadlines began to get to them. Then, the editorship of their hometown newspaper was offered to Bill. It was all they needed. The Robertsons returned to the States and they adopted a life style that could include having children.

Two years later, Kathy became pregnant. However, the child was stillborn. After that, the couple hesitated to risk another pregnancy, but 5 years later it did happen.

By this time, Bill and Kathy had acquired added knowledge about childbirth in persons their age. They were alert to the possibilities of Down's syndrome. Both knew that while mothers under 30 have one in 1500 chances of having a child with Down's syndrome, the chances increase with age until a mother over 45 has one chance in 40. Kathy was 42.

They learned that Down's syndrome was caused by what Bill called, "messed up chromosomes." Either there was an extra one, or some broke off and stuck to the wrong pairs, or some cells had a different chromosome count than others.

After consultation with their physician, they were referred for genetic amniocentesis. Now that it was possible to draw fluid from the amniotic cavity, study the cells shed by the fetus and determine whether the child would have Down's syndrome, they knew they had to do it. Their habits as reporters conditioned them to seek all the facts as early as possible.

In a simple out-patient procedure, at the ideal time (the 14th week), the fluid was removed by use of a relatively small needle and syringe. The procedure caused minimal pain and discomfort.

They were told it would take two to four weeks before the cells in the fluid could be nurtured enough so a "karyotype"—a picture of the chromosome matchings—could be constructed, and the chromosome compliment of the fetal cells analyzed.

The geneticist comforted them at one point and complimented them at another. Of all persons obtaining amniocentesis, he said, more than 95% find that the child on the way does not have Down's syndrome. The geneticist commended them for wanting to know the facts. In these days of easy abortion, they wondered how many parents arrested the pregnancy, never knowing whether their child would be affected or not.

Three weeks later they received the findings. The child Kathy was carrying did have Down's syndrome. It was hard for them to remember everything the geneticist said to them after that. All they seemed to hear now were broken sentences:

"Some choose not to give birth to a child more vulnerable than the average, so . . ."
"Some choose to accept the initial setback of a child with Down's and . . ."
"Parental expectations must be examined and . . ."
"Antibiotics and heart surgery can make life expectancy near to normal in most cases, so . . ."
"The stability of a marriage needs to be considered in order that . . ."
"The general outlook of the family needs to . . ."
"Society is becoming more understanding . . ."
"Special education is becoming more sophisticated . . ."

When the geneticist sensed their confusion, he asked them if it would help to have a medical social worker meet with them regularly for an agreed-upon period of time. Their concerted response was, "Yes." Now they felt the need to "sort things out" and reach a decision. Arrangements were made for their first appointment within 1 week. They left the genetic center knowing that in the next few weeks they would make one of the roughest decisions of their lives.

Chapter 4

Prevention: The Right to Be Well Born

"The Committee holds that the route to prevention must lie through the expansion and implementation of knowledge of reproductive biology, provision of full health services during the reproductive process, and public education concerning all the strategies available to ensure that every child born is well born, whole and without defect."

The best way to deal with mental retardation is to prevent it from occurring. The President of the United States, in 1971, set a national goal to reduce the occurrence of mental retardation by 50 percent before the end of the century. If the American people have the will to achieve this goal, it can be done—but it will require a serious and sustained effort to apply the means that are available.

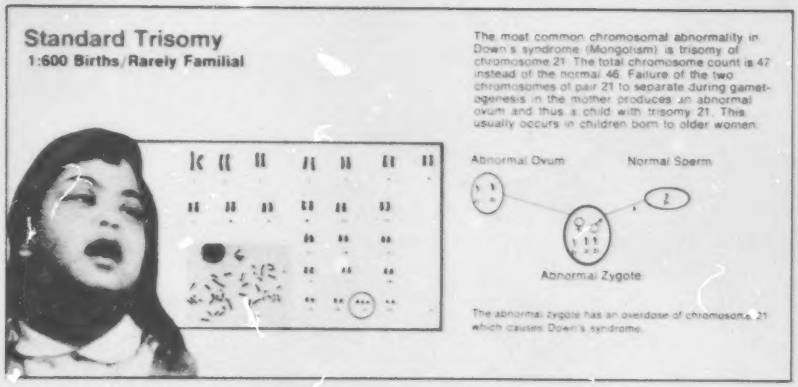
The most severe forms of mental retardation are the result of disorders of the central nervous system involving the brain, usually occurring before birth. We can, therefore, prevent most severe mental retardation by a determination that every child shall be well born.

Milder forms of retardation are usually associated with poverty and social deprivation of the parents and the very young child. We can prevent mild retardation by a determination that every child shall have a good start in life.

These are the legitimate rights of every child. They are achievable goals. To reach the halfway mark in the next 25 years is entirely feasible with the knowledge that we now have. To exceed the President's goal for this century is quite possible if we expand knowledge and apply it at the rate we have done in the past 25 years.

In this chapter, the President's Committee recommends objectives and courses of action to ensure the right of every child to be well born. The following chapter will deal with the right to a good start in our social world.

The possible causes of mental retardation from disorders of the brain are many, but divide principally into two groups, those of genetic origin and those involving insult to the fetus. The former may involve abnormal chromosomes or defective genes. The latter may be related to nutrition, toxic substances, infectious disease, trauma, and other frequently unknown sources. Many of these have their most damaging effects at critical stages of development before birth. The retardation caused by biological factors may range from mild to profound. The patterns of dysfunction may range from specific cognitive disabilities with otherwise intact mentality, through widely varied profiles of abilities, to fairly generalized and consistent deficits in most mental functions.


Standard Trisomy
1:600 Births, Rarely Familial
The most common chromosomal abnormality in Down's syndrome (Mongolism) is trisomy of chromosome 21. The total chromosome count is 47 instead of the normal 46. Failure of the two chromosomes of pair 21 to separate during gametogenesis in the mother produces an abnormal ovum and, thus, a child with trisomy 21. This usually occurs in children born to older women.
Abnormal Ovum
Normal Sperm
Abnormal Zygote
The abnormal zygote has an overdose of chromosome 21 which causes Down's syndrome.

The National Foundation—March of Dimes

Medical technology has made it possible to sustain life and to prolong survival under conditions of disability considered insurmountable 25 years ago. Premature infants of incredibly low birth weight can now be sustained, but at high risk of resultant disabilities. Antibiotic drugs and other forms of medical and surgical treatment can now prolong the lives of severely retarded children who formerly died in infancy or early childhood.

Thus, biomedical advancement has reduced the incidence of mental retardation, but, by increasing the life-span of affected individuals, has increased the prevalence of people who are moderately, severely, and profoundly retarded. The science of preserving life and of healing sickness extends to all and cannot be withheld from those with life-threatening disabilities. The problem of prevention is one which requires solution on many fronts if the occurrence of retardation is really to be reduced.

There are those who would counsel solution through reduction in prevalence; that is, by withholding life-preserving or life-protecting services from those who are severely disabled or malformed. The President's Committee on Mental Retardation does not accept that view.

The Committee holds that the route to prevention must lie through the expansion and implementation of knowledge of reproductive biology, provision of full health services during the reproductive process, and public education concerning all the strategies available to ensure that every child born is well born, whole and without defect.

Much remains unknown about human reproduction and development: the boundaries of knowledge must be advanced. But present knowledge must be applied.

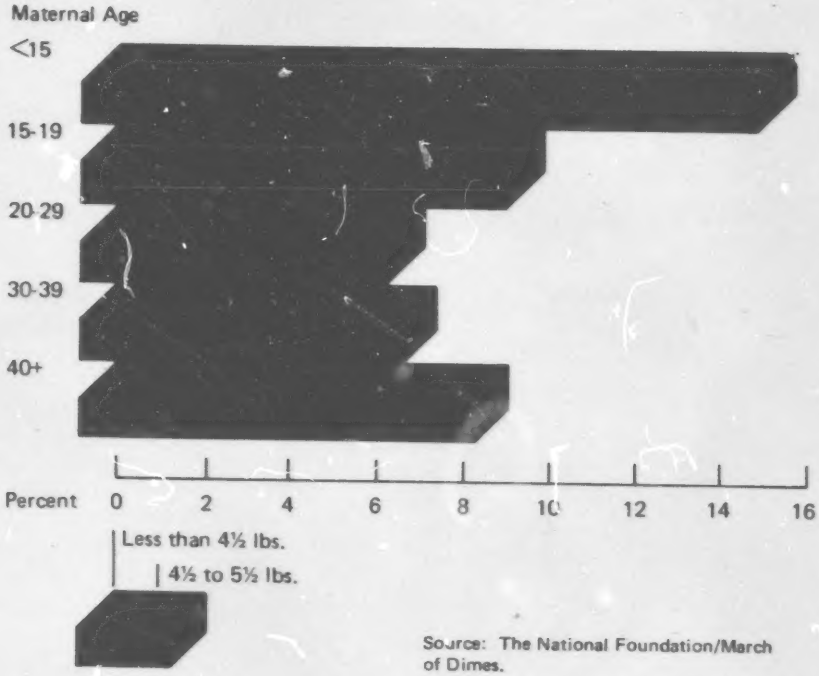
The Goal: Reduction of the incidence of mental retardation from biomedical causes by at least 50 percent by the year 2000.

Significant progress toward this goal can be achieved through the following objectives and the indicated steps to be taken.

Objective I: ***Full commitment of the people of the United States to the prevention of mental retardation from causes operative in reproduction and prenatal development.***

The hazards of being born into this world are many. Some arise from the genetic material, the genes and chromosomes with which the new life begins; some from the external factors which can affect the environment of the fetus to alter its normal development. While knowledge of genetics and of environmental hazards is still limited, enough is known now to provide a basis for markedly reducing the number of babies born with defective mental and physical development. To accomplish this to the maximum degree is not a matter of governmental coercion, but of making available to people the knowledge by which they can choose the best available means of ensuring that their children will be well born. Evidence is overwhelming that parents above all things want to bear children who are whole and without defect. They must, therefore, be provided with the known means of avoiding potential and actual hazards. Financial, administrative and social barriers to this end must be surmounted.

Percent of Liveborn Weighing 5½ lbs. or Less, By Maternal Age, U.S.A., 1973



Source: The National Foundation/March of Dimes.

• *A national education effort supporting planned pregnancies,* which emphasizes optimal conception and maternal health, will be one of the most effective means to reduce incidence of mental retardataion. This effort will ensure the early use of known ways of avoiding the occurrence of mental retardataion.

Every pregnancy should be a planned event, allowing technologies known to prevent mental retardation to be applied. This means that contraceptive education and services must be available and accessible to all persons of reproductive age.

• *Genetic diagnostic and counseling services* are needed by high-risk persons. Outreach genetic services must be extended from university and medical settings to more people in need, especially those in rural settings and in vulnerable population groups.

Persons of high genetic risk are those who have already had a child with severe defect, or relatives with genetic types of disorders.

The means of recognizing high genetic risk should be publicly known and better understood through educational means that dissociate it from stigma and undue anxiety.

Screening of suspected carriers of transmissible genetic disorders, for example, PKU or Tay Sachs disease, should be on a voluntary basis to provide essential information for family planning. This should be one of the services offered by genetic diagnostic and counseling centers.

• Couples should be encouraged to take due account of what is known about the *timing of pregnancies* in terms of maternal and paternal age, and to have their children during the optimal reproductive age.

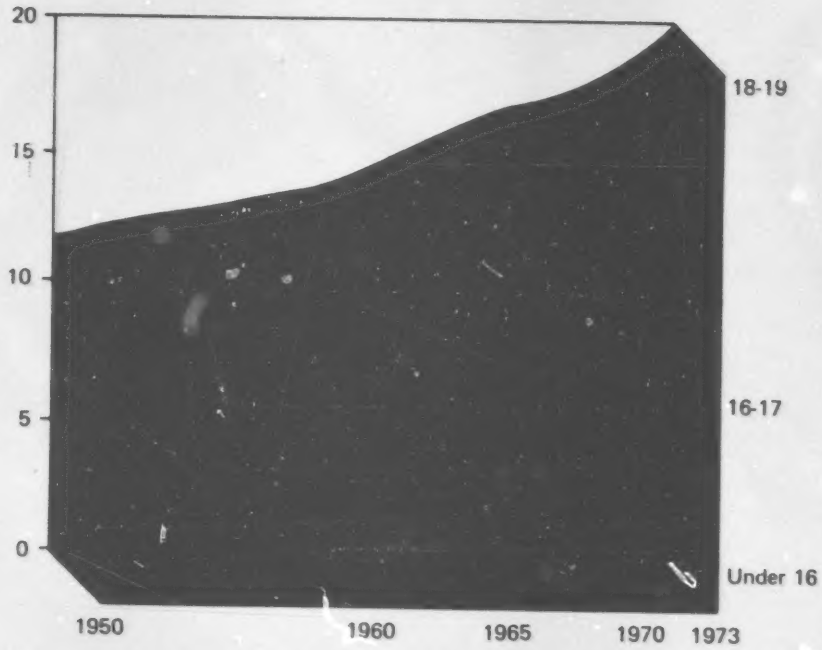
The best age for the mother is between 20 and 35; having children when younger or older increases risk for the child. Aging in the father probably also has some bearing, but its effects are not well documented.

• Couples should avail themselves of all knowledge that will improve the probability of bearing normal children. The *discussion with one's physician of any factor in family history bearing on mental or physical problems* may aid in identifying couples at risk for mental retardation. This may be followed where needed by genetic counseling or application of preventive techniques which can reduce disabilities from inherited factors and allow the birth of normal children.

A good example is the prevention of defect from Rh isoimmunization of an Rh negative mother. Where the Rh incompatibility of mother and father is known, the use of immune globulin at the appropriate time has been found to be an almost certain means of preventing damage in the child from this cause.

For couples at high risk, where preventive techniques are not available, adoptive parenthood should be encouraged as an alternative to their own natural reproduction. Such adoption, where appropriate, should be facilitated by adoption agencies.

Percent of Live Births to Women Under Age 20, U.S.A., 1950-1973



Source: Contemporary OB/GYN, June 1975, as prepared by The National Foundation/March of Dimes.

Objective II: *A health delivery system is needed which assures equal access to quality care at reasonable cost.*

This is a priority of the Federal Government as stated in the National Planning and Resources Development Act of 1974 (P.L. 93-641). PCMR urges the States and the nation to accept this challenge to plan and implement a delivery system that will provide the greatest impact in reducing incidence of mental retardation.

In addition to the general services which should pervade all communities, highly specialized services must be provided on a regional outreach basis from primary university medical centers to affiliated community medical programs. Continued support of the Maternal and Infant Care programs of the Public Health Service, or their equivalent, is of paramount importance.

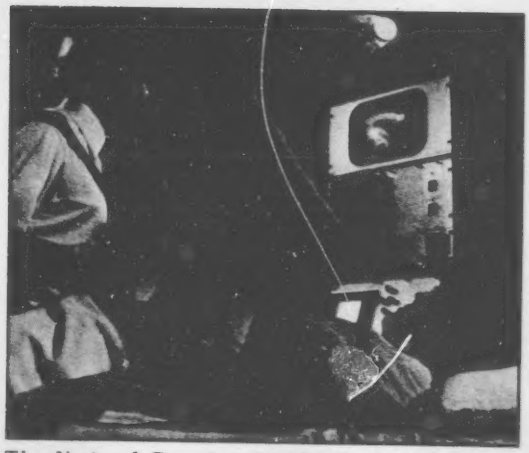
• *Comprehensive maternal and child health care services* must be available and accessible to all women and their children, including those families with low income and those residing in rural areas.

Evidence from many countries, including the United States, is overwhelming that the delivery of comprehensive maternal and child health care is effective in greatly reducing the incidence of maternal, fetal, and infant mortality and morbidity. Ample health services, of good quality and ready accessibility, including both public health preventive services and clinical surveillance services, create the best possibility of detecting and averting the many possible factors which lead to developmental disabilities. In recent years the provision of funds for many of the programs contributory to this end have prematurely leveled off or have been reduced. Support of such efforts as the Maternal and Infant Care program of the U.S. Public Health service (MIC) is especially critical in this regard.

Among the specific health measures that are essential to prevent mental retardation are:

•• Screening for PKU should be continued on all newborns and extended to other inborn errors of metabolism, so that early diagnosis and treatment can be instituted and counseling offered to the parents. States are encouraged to keep abreast of new methods being developed for early detection and special treatment of metabolic and other genetic disorders.

•• Immunization levels must be increased and maintained at a high level to avoid recurrent epidemics of communicable diseases. Some communicable diseases, such as rubella in pregnant women, rubeola (measles) and whooping cough in the child, can cause mental retardation. These diseases can be prevented by immunizations. Increased education, surveillance and treatment programs can minimize the incidence of fetal neurological damage acquired during pregnancy from these diseases and from venereal disease.



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•• Prenatal care that will guard the fetus against damage from maternal kidney infection, diabetes, venereal disease and other hazards should be assured for every pregnant woman from the start of pregnancy.

•• Intensive care should be immediately available for premature and low-birth weight babies, who are at greater risk of mental retardation

• *Exposure of pregnant women to radiant energy sources, infectious agents, dangerous drugs, and other known and suspected hazards* should be minimized until research has clarified the extent of danger these influences pose for the developing fetus.

This requires continuous governmental surveillance and research support, well-designed and effectively conducted programs of public education, and the full collaboration of the health professions in providing current information and counsel.

• *Malnutrition, which is a contributing factor to prematurity, low birth weight, and neurological abnormalities, should be decreased* by all means available, including public education on known nutritional hazards, accurate consumer information on nutritional values of processed foods, and by selective supplementary diet for high-risk pregnant and lactating women and their children.

The full nature and impact of malnutrition is not known; however, in concert with intensified research efforts, good nutrition is an essential safety precaution in the prevention of developmental defect.

• *Routine periodic developmental assessment of all pre-school children from birth* should become a normal and accepted part of child-rearing practices in order to detect and treat incipient developmental problems at an early stage.

The best methods of the conduct and content of such periodic reviews should be continuously under scrutiny by the American Academy of Pediatrics, with the encouragement and support of the Public Health Service. The current provision of Title XIX of the Social Security Act (Medicaid) requires the inclusion of early and periodic screening, diagnosis and treatment (EPSDT) for eligible individuals under 21 years. This applies to health care for the medically indigent. Similar provisions should cover *all* children, at least in the early years.

To achieve our prevention objective, we must not only make such procedures available, but ensure that they are utilized.

Opinions differ on the issue of mandatory *versus* voluntary access to health services. Public policy should be resolved on this, but in either case, the hope of effective prevention and amelioration of developmental disorders lies with a utilization of health services as nearly universally as possible.

Developmental delay may result not only from biological but also from social environmental causes. This point is therefore equally applicable to the recommendations of Chapter 5.

• *Programs for prevention and treatment of child abuse* are necessary to reduce risk of brain damage. Physical abuse of children can cause neurological damage, including mental retardation. It should be noted that some children with mental retardation are at an increased risk of being abused.

• *Persons with mental retardation must be served in all health*

care systems, both medical and dental, available to the general public.

Past tendencies to minimize or deny corrective and therapeutic services to mentally retarded persons, especially those of severe and profound degree, must be reversed in order to avoid compounding the impact of mental retardation on the possible development and functioning of the individual.

- To reach all persons in need, a *more equitable distribution* of *health manpower and resources* must be developed. Medical, communications and transportation technologies must be more broadly exploited.

- *An interim system of cooperative funding* can provide the needed preventive and ameliorative health care during the next decade. Intensive study of its operation can lead to development of subsequent funding systems during the balance of the century.

Although the present chapter is concerned with preventive measures, it is impossible to separate preventive health services from ameliorative and supportive health care services. As the evolution of National Health Insurance programs continues, special attention must be given to provisions for catastrophic costs of prenatal, perinatal and post-natal defect. State laws are now rapidly developing to require health care insurance coverage of all newborns, from the moment of birth, in contracts offering dependent coverage. This principle should be extended to all cases involving the catastrophic costs of severe and profound deficit. It appears actuarially feasible to provide coverage to expectant parents for life-long costs of care for a child with developmental anomaly requiring such care. The existence of such insurance would remove one major deterrent to the provision of life-supporting treatment to severely defective infants.

Systems of accountability must be developed to assess cost effectiveness in health care delivery while providing the best quality and maximum coverage available.

Whenever possible, services planned for citizens in general must be sufficiently flexible to accommodate the demand for services expressed by individual retarded citizens. Evidence of effectiveness in serving mentally retarded persons should be considered in subsequent modification of the national plan.

- *More rigorous identification and eradication of toxic substances* in the environment, such as lead paint, airborne lead, or waterborne mercury compounds, and specific organic toxic compounds, should be pursued.

This effort should be linked with the public education programs on environmental hazards recommended elsewhere in this report.

Objective III: *Continued advancement of knowledge through research.*

Research must be conducted in many areas in which impact on mental retardation is known or suspected. Where causes of mental retardation are understood, research should focus on prevention, early identification, and amelioration. Basic research, targeted research, and research on the behavioral and chemical environment are needed New and improved techniques and approaches are required for this endeavor. Through the year 2000 there must be continuous research effort, with vigorous action taken in response to research findings in order to reduce incidence of mental retardation.

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- *Advancement of basic information in reproductive biology* is needed in order to understand and to ensure normal fertilization and gestation and to reduce incidence of genetic error.

- *A broader understanding of fetal development* will offer options for diagnosis and treatment in the prenatal period.

- *Research is needed to improve contraceptive alternatives* to reduce unwanted pregnancy and allow optimal planning of reproduction.

- New approaches and techniques are needed for *improved research analysis* of such complex medical/social problems as nutrition, child abuse, drug abuse, and environmental hazards, and their effect on incidence of mental retardation.

• *Research methods are needed to explore child growth and development* following maternal disease during gestation, obstetrical complications, prematurity, and prolonged respiratory support. Continued fetal research is needed to assess the impact of environmental agents which may have toxic effects, or produce congential deformity or genetic mutation.

• *The effects of maternal drug use and drug abuse* on the fetus require research.

• Emphasis should be given to those *goal-oriented research programs* that address identified problems and produce the most cost-effective prevention of mental retardation, but not at the expense of broad basic research.

• *A major effort is needed to bring together separate research findings* systematically for more effective compilation, technical implementation and application to prevention.

The following stages in the discovery and use of new knowledge must be implemented by development of more effective information systems to supplement traditional approaches.

•• Discovery of new basic knowledge.

•• Translation of new knowledge into technological application and field testing.

•• Transmission of knowledge and application to implementing agencies.

•• Development and evaluation of new service approaches.

• *An effective information center should be established at the national level* to identify and monitor current research related to prevention of mental retardation in order to improve the flow of information and its application in service delivery.

Such a body should be representative of major professional disciplines involved in critical research fields, service delivery, governmental agencies, and consumer groups. Its composition should have top quality of competence.

The coordinating body should be provided with sufficient financial support to be effective and should be held accountable for the achievement of results.

• *A coalition to include private, public, and consumer groups* is needed to gain broad support for biomedical, behavioral, and environmental research designed to prevent or ameliorate mental retardation.

• *Public education* must be developed to create understanding of the benefits to be derived from basic biomedical, behavioral, and environmental research.

• *Research and demonstration programs are needed to further develop effective strategies for facilitating advancement of young developmentally delayed and mentally retarded children.* Such programs must be field-tested on a broad scale before being implemented on a massive basis.

Research and demonstration projects to date have shown that stimulation and training techniques can be successful in many individual cases and the line of investigation should be pursued.

Objective IV: *A total campaign of public education on the known means of preventing mental retardation must be developed.*

The parents' wish to bear a normal child should be met by making relevant information easily accessible prior to and during pregnancy. Using the schools and the mass media as channels for reaching the general public, and professional training programs and journals for reaching those who can influence people's health behavior, the campaign should aim at the most widespread dissemination and application of existing knowledge.

• *School curricula* at all appropriate levels should include information on the following subjects related to parenthood:

Human reproduction;
Growth and development of children;
Importance of the parent-child relationship in the social, emotional and cognitive development of the child;
Hazards of some modern lifestyles to the birth of normal children.

• *Education for health-related careers* should include training in the following areas:

Consumer participation and social problems;
Inter-disciplinary team collaboration in patient care;
Administration of multi-disciplinary service programs;
Preventive and public health aspects of all health specialties in relation to problems of mental retardation and developmental disability.

• Various chemicals, some medications, and excessive amounts of alcohol and nicotine during pregnancy can increase the risk of having a mentally retarded child. *Women should be impressed with the importance of seeking their physician's advice* before using any such products when planning pregnancy.

• *The public should be informed that chemical and other environmental pollutants exert unknown but potentially hazardous effects on the developing fetus.* Such awareness should provide added impetus to the necessary research and enforced controls of environmental hazards.

• *Obtaining medical care early during pregnancy* ensures the best opportunity to monitor both the mother's and the baby's health. The importance of such early care should be brought before the widest possible public.

Thomas Mendez

"Definitely not mentally retarded, and misplaced in an EMH class."

It's not the usual game that children play when they don't want to go to school. Quiet Thomas Mendez gets up and starts to get ready, but part of him—his stomach—rebels violently, even to the point of vomiting sometimes. His mother, Ramona Mendez, who is not one to give up, casts about in her struggle to do the right thing for her 8-year-old son. This is just one more of the many problems that have come to the Mendez family since they moved to Metro City from Puerto Rico five years ago.

It was three days after New Year's, 1970, when Ramona and her husband, Alfredo, decided to move to a land of "better opportunities." Thomas was 3 and little brother Roberto was 1. When they arrived, they found there were few jobs for Puerto Ricans. Ramona was able to serve as a domestic worker, but Alfredo, like other men in the ghetto, was unable to find any kind of work. Both attended English classes in the evening, hoping this would make things easier. Three years later, the family had to go on welfare. Mr. Mendez, overwhelmed by a sense of helplessness, deserted.

Thomas' first year in school was bewildering. His teacher filled out a form, stating her belief that this Puerto Rican boy was mentally retarded. Thomas was automatically transferred to a class for the educable mentally handicapped (EMH), and placed on a waiting list for testing. Mrs. Mendez was not notified of this shift. Three months later a psychological examiner —who was neither familiar with the Spanish language nor the culture—reported that Thomas was "mentally retarded in the mild range." It was recommended that he remain in the EMH class. When Mrs. Mendez finally received notification that her son was retarded, she refused to believe it.

Mrs. Mendez sought help from a community action group of parents and professional people who secured private psychological testing by a Spanish-speaking psychologist. This psychologist found Thomas "definitely not mentally retarded, and misplaced in an EMH class." The school sent Thomas back to a regular first-grade class. But he was now far behind the rest of the students. Language problems and cultural misunderstandings made it all the harder for the young boy to catch up. Going to school became a hell for Thomas Mendez.

When the mother asked school officials for help, they told her to be patient. They promised to make many changes that would include more bilingual teachers who could understand and teach children with Latin American backgrounds.

Members of the community action group told her the school system had been making promises like this for years, but nothing had happened. More than half of the Spanish-speaking children in EMH classes, they say, are misplaced because regular classes are geared for the white middle-class language and culture.

The community action group asked Mrs. Mendez to sign as a plaintiff with other parents in a class action suit against the public school system. The pleadings would call for psychological tests and procedures that would not discriminate against children because of racial, cultural and linguistic backgrounds. They would ask for compensatory education to repair the educational and psychological damage which resulted from misplacement in an EMH class. They would strongly urge bilingual education so that going to school could be a happy event and not a childhood nightmare.

Mrs. Mendez must decide what is best for her son. Should she believe the promises the school officials made, or should she join with other parents in a lawsuit against them? In the meantime, Thomas' process of learning is far from joyful and his stomach continues to rebel.

Chapter 5

Prevention: The Right to a Good Start in Life

"A serious effort to reduce the occurrence of mild forms of mental retardation must attack the root causes in depressed, disrupted, and impoverished environments."

Mental retardation, especially in mild forms, tends to be more prevalent and more devastating among disadvantaged social groups. In perhaps 85 to 90 percent of cases, mild retardation, not involving identifiable organic or physical cause, is associated with conditions arising from the environment, poverty, racial, and ethnic discrimination, and family distress.

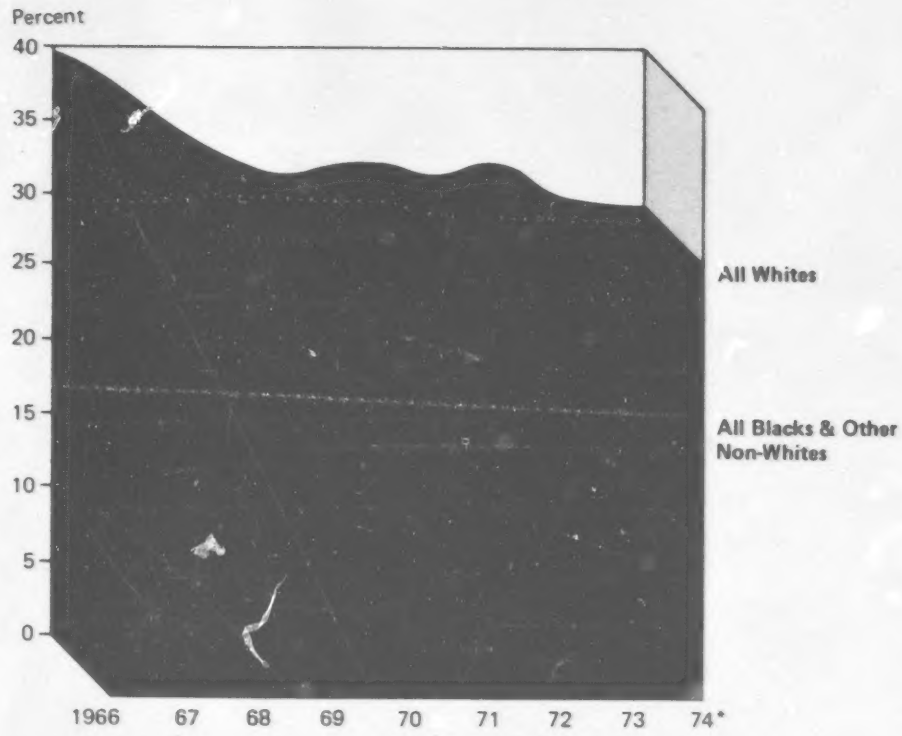
The quality of life represented in the kind of nurturant care and stimulation which the child experiences in the very early years may substantially and perhaps permanently influence his or her cognitive functions as well as physical health.

Consequently, a serious effort to reduce the occurrence of mild forms of mental retardation must attack the root causes in depressed, disrupted, and impoverished environments. The problems are massive and difficult to resolve, but their resolution will reduce the frequency not only of mental retardation, but also of other social ills associated with poverty. Failure to resolve the root problems condemns society to the perpetual recycling of all those ills, including retardation.

Poverty in itself produces magnified hazards to life, health and human development, but when it is accompanied by racial and ethnic discrimination, cultural deprivation and family disintegration, the consequent disadvantage is multiplied many times over. This is the case on the American scene most frequently among Blacks, Spanish-speaking, Native Americans, Asiatic groups, and multiple disadvantaged urban and rural whites. Members of these groups appear among those identified as mentally retarded in numbers far out of proportion to their presence in the total population. This cannot be ascribed to inherent racial, ethnic, or familial defect, but to social, economic, and educational disadvantages to which these groups are subjected. The problems we refer to are not limited solely to ethnic groups nor do they characterize all members of such groups. They haunt the scene of poverty, however, in Appalachia as well as on the Rosebud Reservation, in Harlem, and in the San Joaquin Valley.

Our industrial society is technically capable of producing enough material wealth to support the human population adequately. Our Constitution and moral principles guarantee standards of equity and justice in the opportunity to achieve a decent life. The perpetuation of social misery is at enormous cost to the whole of society in dollars and in lives. Part of that cost is in the three to five million individuals in the United States who suffer impaired mental development as a consequence of their social and cultural disadvantage.

Poverty Rate by Race: 1966-1974



*Poverty: Income cutoff for non-farm family of four, $5,038 (1974).

Source: Bureau of the Census.

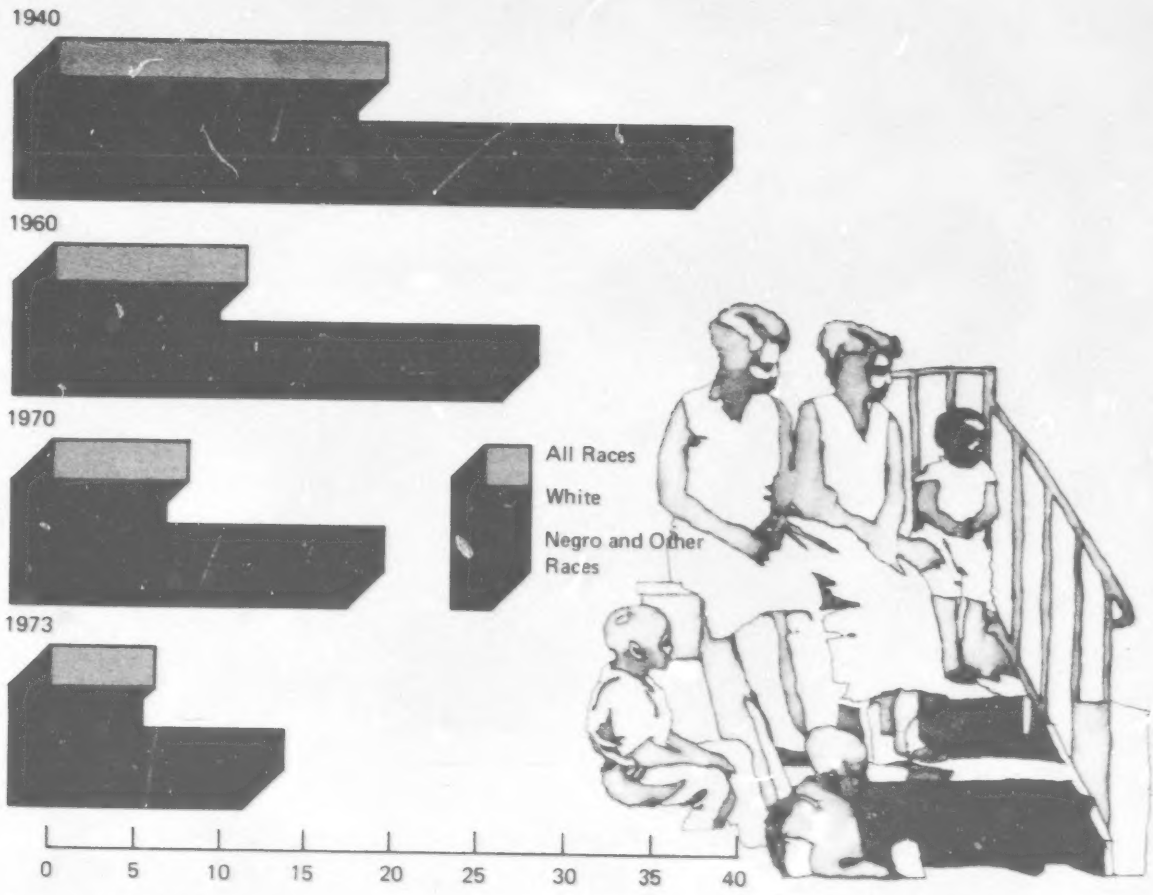
Goal: To reduce the incidence and prevalence of mental retardation associated with social disadvantage to the lowest level possible by the end of this century.

This goal can be accomplished through the achievement of the following objectives by means of the steps indicated.

Objective 1: *Elimination of prejudicial attitudes and discriminatory practices based on race, ethnic membership, ("racism") or social class as a root source of impaired or retarded human development.*

- The President of the United States, the Congress, and the Courts must exercise continued leadership in the *elimination of attitudes and practices that create disadvantage* to minority persons in achieving their potential human development.
- Affirmative action in compliance with statutory requirements must be vigorously implemented to *assure that minority and disadvantaged individuals will be appointed* to boards, commissions, and administrative positions with decision-making responsibility on matters affecting the developmental opportunity of all persons in need.
- *The selection of personnel in all departments to administer Federal and State programs* designed to meet the needs of poor and minority group persons must include consideration of appropriate experience, training, and sensitivity to the special problems, attitudes, and value systems reflecting ethnic and economic differences.

Households Living in Crowded Conditions, By Race: 1940, 1960, 1970, 1973



Source: Bureau of the Census.

• *Community Action Programs* should be continued and funded on a national level with emphasis on greater involvement of poor and minority persons in decision-making and on the creation of a climate of self-esteem and personal worth conducive to personality growth and mental development.

Objective II: *Improvement of home and community environment and living experience through a persistent attack on conditions which impede or distort full development of human potential among poor and minority groups.*

The chronic problems experienced by people in certain social environments have created an impediment of long standing to child development and must be resolved as rapidly as possible. Continued failure to do so produces increased danger of acute social disruption or of unresolvable impasse, to the irreparable detriment of developing children.

These focal social situations involve migrant workers, Indian reservations, deteriorated inner cities, and isolated or deteriorated rural areas. In all instances, the conditions of poverty, unemployment, and family deterioration breed conditions essentially hostile to healthy development of children and youth.

• *The national Home Start* program to assist low-income parents in the early developmental training of their children in their own homes should be developed systematically as knowledge and experience expand. This effort should use the best means available to stimulate the cognitive development of children through parent-child and other social interactions, with due respect for cultural differences.

Many of the developmental lags, exhibited by children in Head Start and other preschool programs, could be reduced or prevented by programs reaching into the home to assist mothers and other family members in the care and nurturance of babies and very young children. Over 300 Head Start programs are using the Home Start approach along with the classroom-based Head Start. Enough experience has been gained from demonstration projects in varied types of communities to warrant expanded efforts. Experience in early education regarding methods of stimulation, qualification and type of personnel, ways of teaching parents as well as children can be put to use in these Home Start projects. Funding possibilities under Title XX of the Social Security Act, and other governmental and nongovernmental resources should be explored.

• *Continued and sustained research* at basic and applied levels must be supported by appropriate Federal agencies to develop knowledge and implement the best means of early assistance to families and children at risk from psychological and social hazards.

• *The total home and community environment must be improved* for minority, poor, and otherwise deprived people in areas such as housing, health services, recreation, employment, and nutrition.

• The current welfare system should be revised to provide for the training and utilization of *welfare service workers indigenous to the neighborhoods* to which they are assigned. Based on intimate knowledge of their constituencies, such workers would provide welfare recipients a basic consumer education relating to purchase and preparation of food for adequate nutrition, making and buying clothing, purchase of needed services, and other aspetcs of home and family management.

The emphasis in this recommendation is on (1) the membership of the service worker in the community environment being served, (2) the direct interaction between worker and recipient, (3) stimulation of self-reliance in the recipient, (4) guidance to specialized sources of service only as necessary.

The training of such workers should be fostered in the community outreach and extension programs of higher education in the social welfare and consumer education fields.

• *Access to child development centers* for poor and minority group children should be on an equal basis with all families in need of such service. This would be supplemental to home-centered training programs recommended above. Such centers should be strategically designed and located to serve both urban and rural communities.

• *Monetary aid must be provided to low-income parents for education and employment training* as a means of improving the economic and psychological life of the family.

• *More direct health services to needy families* should be provided on a progressively improving basis. Such services should stress preventive and ameliorative measures of all kinds relating to hazards to child development and mental functioning.

Objective III: *Equal educational opportunity for all persons, encouraging cultural differences without penalizing and damaging development.*

• *Methods and procedures must be improved for determining the educational needs of individual children* exhibiting problems in school. Labeling and assigning children to classes for the mentally retarded by cursory procedures employing inappropriate tests is discriminatory and unjustified, especially when applied to children from cultures other than those on which tests have been standardized.

Educational programming to meet individual needs, especially of those exhibiting problems of learning, adaptation or social conduct should be based on broad psychological and social assessments, whether formal or informal, which have the following characteristics:

•• They are conducted in the language of the child's living environment.

•• The means employed are designed to yield a descriptive profile of a broad range of cognitive and adaptive performances, rather than a global assessment measure.

•• The assessment procedure is culturally sensitive, where possible in the standardization of the instruments used and, in any case, in the qualification of the assessor.

•• Prognosis is made with caution and on a tentative basis, the assessment being used primarily as a guide to individual program development rather than for categorical classification.

There is need for continued efforts to improve the quality and effectiveness of assessment techniques while making the most constructive use of methods and instruments currently available.

• In support of the previous recommendation, *broad programs of educational research and development* should be Federally funded over the next 25 years to discover and develop the best approaches to equitable individualized education for all children, including the development of improved, culturally sensitive assessment methods.

• *Curricula for certification* of teachers, administrators, and other educational personnel should include courses focusing on both the positive and negative impact of racial, ethnic, and economic factors on human development. Such curricula should focus on:

•• *sensitivity* to the hazards of cultural bias and prejudice to individual development.

•• *contributory values of cultural diversity* and the contribution of varied ethnic groups to the common culture of all.

•• *assistance to children* in examining their own attitudes toward minorities including the minority of mentally retarded children.

•• *selection of textbooks* and other media of instruction which appropriately and adequately reflect the realities of ethnic and individual diversity.

•• *creation of learning environments* which will minimize feelings of cultural exclusion and disadvantage and augment feelings of acceptance and participation.

• *Teachers working with children who are in any way disadvantaged should be specially trained* and qualified and should receive commensurate salary and advancement incentives. This is designed to eliminate the still-persisting tendency in some school systems to assign inferior or incompetent teachers to work with disadvantaged, handicapped, or behaviorally different children, and to practice other forms of covert discrimination which have the effect of increasing rather than reducing disadvantage.

There should be opportunity for in-service and continuing education or retraining not only for teachers but also for all educational personnel working with disadvantaged children, including administrators, nurses, guidance counselors, social workers, and other special resource personnel.

• *Higher education institutions should develop outreach programs* of continuing education and field-based programs of training associated with community service settings. A major focus of these programs should be on upgrading the quality of life of poor and minority groups and on the prevention of environmentally related retardation.

• *Minority institutions of higher education* are uniquely qualified to deal with problems experienced in minority and poverty settings; therefore Federal funding activity should take advantage of this expertise and ensure that it is utilized to the greatest possible extent. Minority colleges serving primarily the disadvantaged must receive an equitable share of State and Federal funding. Present statutory provisions requiring equitable funding and affirmative action on personnel practices must be positively implemented.

The role of traditionally black colleges, both private and public, needs careful attention to the end that while integration takes place, the unique values and contributions of the black background may be utilized to the fullest extent. The community colleges currently developing on the Indian reservations need strong encouragement and support as a primary resource in the resolution of problems faced by those communities, especially in the training of indigenous health care and service personnel.

Objective IV: *Provide adequate controls on the allocation and use of public funds, to safeguard the interests of the populations most at risk from social and economic disadvantage.*

- The Federal Government must assure, within the language of enabling legislation or by *clear designation of legislative intent, how funds are to be allocated* and spent in programs for poor, minority and handicapped persons, and require demonstration of compliance.

This recommendation is specially directed, but not limited to, the use of general and specialized revenue sharing, developmental disabilities, and community development funds by State and local governments.

- Legislation for health, education, and welfare programs must ensure *proper monitoring and accountability* of programs for people who are mentally retarded, based on outcome criteria in the lives of those served.

Provisions of the Developmentally Disabled Assistance and Bill of Rights Act of 1975, Section 110, for the employment of outcome criteria for accountability in use of funds may serve as a model for other legislation.

97/98

"She's 60 years old and adjusting to semi-independent living."

She's 60 years old and adjusting to semi-independent living in a large city. That's not easy after spending most of her life at Walden State School and Hospital.

Mary Pate was institutionalized when she was 5 years old. The earliest records spoke in vague terms of an "irresponsible and indigent" father and mother and of four children being sent to various orphanages and State institutions. The record states that Mary was admitted to Walden because she was "an extremely slow child who is given to fits . . . a serious problem in the community."

Her own recollections of those early years, living on a large ward with women of all ages, are skimpy. "All I can remember is that there was lots of noise . . . there were some you learned to stay away from. I used to hide in a corner."

One of the first significant persons in Mary's life was an attendant who took an interest in her.

"Her name was Mrs. Hammond and she asked permission for some of the younger ones to be in a special group. We spent most of our time in the dormitory making beds. She taught us to make beds so the corners were just right. She taught us manners, how to take care of ourselves and the rules of the institution. As long as you didn't break any rules you wouldn't get into trouble. I always followed the rules Mrs. Hammond taught me."

She remembers certain friends she had as if they were all from one family. There are remembrances of "being a good worker" for many years in the institution laundry. She recalls the utter joy of receiving cards and letters. Usually they came from attendants on vacation. A packet of letters and cards held together by a rubber band is still one of her most valued treasures.

Four years ago, she was placed in a small group residence for women in a city not far from Walden. At the same time, she began work at a vocational training center. After a year and a half of life at the group residence, Mary moved into an apartment of her own.

Today, Mary Pate is experiencing an array of situations—both fearful and hopeful—more complex than any she has known. Here are glimpses of Mary's present world:

- Maintaining an apartment:

"Every weekend I wash my clothes at the laundromat and then I clean and scrub my apartment from one end to the other. My landlord says nobody has ever kept it as clean."

- Vocational Training:

"It's hard working at the workshop. They keep you working so fast . . . I get tired of bolting those two pieces of metal together. I wish I could work in a hospital, making beds."

• About Walden State School:

"It wouldn't be good to go back. All the friends I knew are gone like I'm gone . . . It would be nice to visit. I heard they are building a new chapel . . . Maybe I can send a donation."

• Her seizures:

"I've learned to know when they are coming on . . . when to sit down and rest . . . or lie down. I walk to the University Medical Center to pick up my pills. I never miss taking them. When I do have a seizure, I feel bad . . . like the other day when one happened while I was shopping in Kroger's. That makes me feel wrong. I've just got to be more careful."

• Leisure time:

"The people at the workshop go bowling, but I don't go. They also have dances, but they're no fun either. I'm too old for that. On the weekends I stay in the apartment and clean up. Once in a while one of the counselors and I go out to dinner. Also, I go to the First Baptist Church. I found some friends there. I was baptized. They wouldn't let me do that at the institution. They said I couldn't go under water because of my seizures. That didn't matter here. Now I'm trying to follow the rules of the Baptists."

• Cooking:

"I like to cook my own meals. The counselors helped me to learn how. The things I cook aren't fancy, but I like them. My favorite things are mixed vegetables, celery sticks and raisins."

• Her self-image:

"Do you think I'm ugly? Sometimes I get to thinking I am . . . At other times, I don't. What do you see?"

Mary Pate has come a long way from cowering in a corner on the ward of a large institution. Now she works to master the nuances and rules of a new environment. Sometimes there are fears that the complexities of the city may be too much for her. About that time her own determination becomes evident. For example, she and her community counselor were talking about the coming of the year 2000 A.D. and what life would be like then. Mary asked the counselor to help her figure out how old she would be. When it was clear she would be 85, she responded, "I'd like to live until then . . . and even longer."

Chapter 6

Humane Service Systems

"We may thus speak of 'developmental services,' 'supportive services,' and ...'protective services.'"

The attainment of adequate and humane service systems for the mentally retarded citizen is a major goal of the Committee. It involves three complex areas of concern:

- Are mentally retarded persons treated and served in a humane fashion?
- What kinds of services are they offered? and
- Are the services managed in a planned and accountable way that makes for both efficiency and effectiveness?

The essence of humane service lies in its capacity to

accord dignity to the person served;

allow him or his personal representative the determination of his own purposes;

acknowledge his privilege of choice, and thereby his independence;

permit him to experience shared relationships with others;

allow him his own material possessions; and

assure him of opportunities for meaningful activity consistent with his wants and needs.

The concept of a "service delivery system" connotes the efficient production and distribution of benefits and goods to large numbers in an organized way. But efficiency from the standpoint of a systems expert may produce managerial rigidity that is unresponsive to the unique needs of individuals. Furthermore, many systems are incomplete and require development that is flexibly adapted to local needs and conditions. At a given time they may not embrace all of the services that are possible, and new technological developments in service may not immediately and generally be put into use.

An adequate and humane service system envisions a means of providing service to individuals on their terms, sufficient in quantity, quality and accessibility for all who need them, and capable of providing for unique needs in spite of massive demand.

Services required by individuals who are mentally retarded are broadly of three kinds:

those that enhance the development of human qualities, capabilities, and attributes to the maximum obtainable competency;

those which bridge the gap between attained competency and what is required for normal social independence; and

those which protect the person from excessive hardship, loss of livelihood, sudden disaster, neglect, exploitation, and other threatening circumstances beyond his control.

We may thus speak of "developmental services," "supportive services," and "protective services."

The difference in need for each kind of service between a retarded person and a so-called normal one, is not really a difference in kind but one of degree, and this same principle holds among retarded persons themselves. For example, all children require and receive the developmental service of education; retarded children may need specially designed educational services to fit their particular needs, and one retarded child may need a different pattern of education than another. All citizens depend on the supportive service of public transportation to supplement their limited capabilities of independent locomotion; a retarded person may require some special assistance in making use of public transport. Social security protection, unemployment insurance, health insurance are applicable to all; retarded individuals may require earlier, more continuous and more extensive protection because of the degree of disability and the time of its occurrence. The objective of protective service for the mentally retarded person is to guard against the particular hazards arising from disability.

Obviously, the more severe the degree of developmental disability the greater the need for compensatory developmental services, and the greater the gap that is likely to remain between attainable abilities and those required for normal independence and social functioning. The goal is to lessen the dependence on special forms of supportive service, with protective services standing as a safeguard for use when other resources fail.

For the great majority of those who are identified as retarded in childhood, a goal of "disappearance" from special service is feasible and attainable. For many, continuing special services may be required in some aspects of functioning but not in all; for some, need for special services of one kind or another will be intermittent. For a smaller number who are more severely handicapped, sustained supporting service and extensive protective service on a lifetime basis will be required. In short, retarded individuals will require basically all of the same developmental, supportive and protective services that other people do, but may require varying adaptations or special services in any of these areas to offset their retardation.

Another assumption underlying the recommendations is that development itself is a life-long process of change. There is no time at which development ceases except with the termination of life itself. Thus, there is always a process of learning which must accompany the changing stages of life to provide personal resources for coping with circumstance. Much of this learning is self-generated by unfolding experience, but much can and should be fostered by the agencies of society. This need is not unique to the retarded population—continuing education is a prominent feature of contemporary life—but many of them will have special requirements.

The possible service needs are legion and constantly changing with the movement of social and indivudual life. Therefore, any list suggested will be general and incomplete. Emphasis here is placed on the conditions and broad characteristics which service delivery must have to realize the envisioned goal for this century:

Adequate and humane service systems for all retarded persons in need of them

This goal can be realized through achievement of the following objectives and the steps indicated for their progressive realization over the next 25 years.

Objective I: *A comprehensive array of service resources available to meet the essential needs of all retarded persons in all sections of the United States.* The essence of such resources is that they be responsive to the needs of the individuals served for developmental, supportive and protective services. They must offer ready information, access and continuity, as well as adaptation to ethnic, geographic, and economic differences of communities. The array of services must be well-known to the community and so ordered as to provide a continuum of care as needed.

With the emphasis on the retarded person as citizen, it follows that he should be served insofar as possible through the normal channels of community public services, e.g., in the schools, transportation system, public and private health service, etc. However, to accommodate retarded citizens to the degree that their individual needs are at variance from the norm, generic community services must become more flexible and develop a willingness to adapt to such differences within reasonable limits. There is no justification for exclusion from any service solely on the basis of identification as "retarded," but only on the basis of specific characteristics which make the normal service inappropriate. For example, all children may benefit by the correction of strabismus (crossed eyes); to deny correction on the ground of retardation is unreasonably discriminatory. On the other hand, speech correction for a child with Down's syndrome must accommodate to the difference in structure of the oral cavity and tongue and to the delay in language development.

As a general principle, when the service needs extend beyond the limits of the generic system, special services must be provided.

The practical limits of relying primarily on the generic system, as in "mainstreaming" in education and in other service settings, are still unknown and will doubtless change as needed research and the evaluation of pilot programs move forward.

The comprehensive array of services called for must deal with the issues of

•• generic versus specific systems;

•• equity of access to services for all retarded citizens, especially in inner-city and isolated rural areas; and

•• the means of combining service components to meet the needs of the consumer rather than merely the administrative and fiscal convenience of the providers of service.

The principles of the service delivery system of a community as expressed in *Standards for Community Agencies Serving Persons with Mental Retardation and other Developmental Disabilities*, AC/FMR, Joint Commission on the Accreditation of Hospitals, include the following:

•• *Responsiveness*, which focuses on the needs of the unique community area served, and is expressed through response to the specific developmental needs of its clients.

•• *Availability* of a sufficient array of components actually present to meet the array of needs known to exist.

•• *Accessibility*, reflected in an affirmative action policy and operating procedures that minimize the effect of all potential barriers to service utilization by those who need it.

•• *Individuation*, which provides mechanisms for selective choice in the array of services most suited to each person, according to his needs.

• *A minimum array of essential developmental, supportive, and protective services* must be guaranteed to all mentally retarded persons by Federal action in collaboration with the States, as a first order of priority. Services beyond such minimum levels must be developed and supported on a timely schedule.

It is difficult to state with any degree of assurance what constitutes an absolute minimum. The list given in Chapter 1 above is fairly inclusive, but many of the items can be provided at various levels of sufficiency. In any community, fundamental personal rights and interests must be protected. There must be

•• provision for residence under developmentally advantageous conditions;

•• physical and social maintenance;

•• educational opportunity;

•• health care;

•• some form of personal counsel, advocacy, or representation.

These elements constitute basic life-support services. Beyond that it is obligatory that a full complement of protective, developmental, and supportive services be in the making, on a sound, feasible, and humane foundation of public policy.

• *Services must be equitable and delivered according to need;* provided through public, voluntary, or purchase sources, with emphasis on access by choice; delivered at an adequate level of quality by competent manpower selected for its trained capacity to meet service objectives; focused on helping retarded persons achieve the highest possible levels of personal and economic independence.

PCMR believes that *direct access by choice requires some form of direct cash or voucher system;* it therefore recommends the immediate support of research and demonstration projects, in selected communities representing a variety of social environments, to test the efficacy of such systems; it further recommends the expeditious implementation of the system found to be most effective in supporting direct access to services by consumer choice.

• Inter-departmental policies at Federal and State levels should emphasize *coordinated, simplified, and unified procedures for application and eligibility determination,* so that mentally retarded consumers can get the services they need.

Promulgation of information and regulations must be coordinated among departments, mutually consistent, and effectively distributed both through service outreach methods and through written materials. Such information should be simple, complete and current. (See Role of Government, Chapter 9.)

In the series of Regional Forums conducted by PCMR during the past two years, one recurrent plea was heard above all others: "Cut through the bureaucratic red tape with clear-channel communication lines!" This was chiefly directed toward Federal agencies, but frequently involved regional offices and State apparatus. Concern was also expressed that the regulations issued by government agencies were preoccupied with exclusionary rules for eligibility for service, to the neglect of methods of prompt and effective delivery.

Numerous instances of contradictory policies that threaten or eliminate intended program benefits are regularly brought to PCMR's attention by consumers and by direct providers of service.

Objective II: *The exercise of free choice and decision by every retarded person or his personal representative in matters that concern his interests.* This includes his place and mode of living, the services he wishes or needs, and the person or agent he wishes to represent him and to protect and promote his free movement among service agencies.

The emphasis in this objective is on the exercise of the same rights of free choice and decision that are normally exercised by the citizen in the community, recognizing that in many instances the degree of disability may require the action of a surrogate or representative in his behalf. This, again, is only an extension of the citizen's right to seek counsel and the public service of protecting that right.

• *No major decision should be made on behalf of a mentally retarded person except by himself, or by an agent* whom he or a duly constituted authority designates to speak for him; this principle must be established by law, regulation, and judicial initia-

tive, and should be assured by HEW, the Department of Justice, and the States.

The principle recognizes the normal scope of decision made by parents in behalf of their minor children, and by guardians for wards that have been declared incompetent. The essence of the principle asserts, however, that *the options of choice reside in the person* rather than in external agencies which provide services or manage their supply. Service-providing agencies are, however, accountable for application of eligibility standards and expenditures as provided by law.

• *Administrative procedures of service agencies must reflect the right of the mentally retarded person or his personal representative to select freely any service of his choice* for which he is eligible and to express need and demand for those services which his disability requires. This includes the right to coordinate such services for his own unique purposes and to change service agencies at will, as other people normally do. To this end, all Federal agencies and the States should officially recognize this principle through policies, regulations, and affirmative action.

This provision does not in any way limit the right of the person to professional advice and counsel, or the right and responsibility of service agencies to give it, but does protect the individual from subjection to services or service goals contrary to his desires and interests. The right of choice is transferable only under due process provisions as elsewhere provided. This provision has the effect of reinforcing the normalcy of choice as a function of life in a democratic society.

• The exercise of meaningful choice or decision requires a basis of *informed participation and consent*. Consequently, all Federal agencies and the States must provide suitable means of guaranteeing mutual understanding on any matter requiring choice and decision affecting a mentally retarded person.

Objective III: *The availability of a personal representative for every mentally retarded person who wishes or requires one.* Such a representative will serve as the person's agent in understanding and articulating his needs and in negotiating services or combinations of services which are at any time essential to meet the person's unique requirements.

There are a number of different ways in which a person in need may be served by another person or agency as "intervener" between the individual and the providers or regulators of services. It is essential to distinguish these:

•• The natural function of the parent of a minor child, who acts as the legal representative of the child and makes decisions in the child's behalf which the child is incompetent to make and expedites or vetoes desires which the child may express. Parental authority is limited by rights which inhere in the child. Normally, the natural and legal authority of the parent to make decisions for the child without his consent terminates when the child reaches legal majority age. Parents may, however, continue to serve in an advisory, advocacy, or, if circumstances warrant, in a legal guardianship role.

•• A legal guardian is a person or agent assigned by law to exercise certain rights in behalf of a person judged incompetent to exercise them in his own behalf. This may take the limited form of guardianship of the person, or of conservator of the person's property, or may comprehensively include both. Retarded or otherwise disabled persons have the right to the appointment of such legal guardians in all States. There is, however, need in many States to improve and refine the laws to preserve to the individual the exercise of those functions of which he is capable.

•• Case workers or "case managers" are commonly assigned by service agencies to implement the delivery of services to a person in need. The functions of the case worker are determined by agency regulation and policy, usually involving determinations of eligibility and attempts to arrange delivery of the agency's services in a form judged by the case workers to be in the best interests of the client. The case worker may arrange referrals to other agencies and may, in some instances, develop a relationship to the client resembling that of a personal advocate, but the basic role is that of an *agency* representative.

•• An ombudsman is a person assigned by government or other authority to assist individuals from a neutral standpoint in the resolution of problems or grievances in relation to that authority.

•• A personal advocate (citizen advocate) acts in a one-to-one relationship with an individual, combining the roles of friend, protector, and representative. As developed by the associations for retarded citizens, the citizen advocate is generally a volunteer, working within an organized program. He has received some training and supervision in performing the role. He meets the need of the retarded person for someone who takes a personal interest in him, sup-

ports his own initiatives, and provides a degree of surveillance over the services he receives and his general wellbeing. The advocate intervenes in his behalf when indicated, but without the surrogate authority of a legal guardian.

•• The service broker is a person or agency sufficiently skilled to understand the needs and desires of clients, to know the service entities and resources available for the satisfaction of those needs, and to negotiate for access to them. The service broker is independent of the providers of service, but does not sustain the personal relationship to the client that is characteristic of the "citizen advocate." At the present time, the function of service broker does not exist as an identifiable occupation in the field of social services generally or of mental retardation in particular. As the systems of service delivery within the community develop, they tend to become complex in their variety and baffling to the consumer, especially the consumer with limited intellectual capacities. Hence, PCMR envisions the useful role to be played in the evolving service delivery systems by such an occupation.

In the recommendations which follow, PCMR is concerned to promote *all* effective means by which the retarded citizen may select and utilize representative persons and agencies to assist him in carrying on the most satisfactory and self-reliant life in the community that is possible for him. The roles of parents, guardians, case workers, ombudsmen, citizen advocates, and service brokers are all of importance in their various ways. Emphasis here, however, is placed especially on the last, the professional service broker, as representing a potential source of support of great promise in the unfolding future for the retarded person in the community. There is no reason, be it noted, why such a professional function could not be of great value to citizens generally.

• *Public policy must assure to every mentally retarded person or his legal guardian opportunity and means to select or employ an agent or agency as his personal representative*, to negotiate on his behalf for any available service he requires, no matter how brief or extended his need for service may be. Such policy should be embodied in law and regulation, and must provide for funds or credits to assure to each retarded person the means of free selection of such an agent. The agent or agency selected as a personal representative must be completely independent of any serving agency or system, except that recognition and qualifications for such representative should be established by law.

• In order to *stimulate the supply of persons qualified to give competent representation as service brokers to mentally retarded clients*, and to protect against exploitation by unqualified agents, HEW and the States should provide by statute and support for the recruitment, training, and certification of persons with the knowledge and skill necessary to perform this function. Competency qualification for service as a personal representative if public funds are involved would require (1) basic knowledge of mental retardation and the needs which may be associated with it at various ages and stages of development; (2) knowledge of the rights and responsibilities of retarded persons in relation to the principal aspects of living; (3) knowledge of the State and community and its resources for meeting the needs of retarded persons; and (4) direct experience of a supervised nature in relation to the personal and social adjustment of retarded persons. Such qualification could be obtained through specialized training programs administered by colleges, universities, and professional schools. It is recommended that grants to support research and demonstration projects for this purpose be instituted immediately.

Objective IV: *Maximum opportunity for every mentally retarded person to live in a local community setting of his choosing.* Where a person lives is the foundation on which his utilization of developmental and supportive services must rest.

The issue of "deinstitutionalization" is fourfold:

•• provision of a sufficient variety of residential alternatives in the local community to meet individual need and preference;

•• local availability of adequate services to provide for maximum personal development, personal freedom, and productive personal living;

•• elimination of obsolete features of public and private total care institutions and their modification to serve specialized functions; and

•• developmental preparation of the person currently living in an institutional residence to move into a more independent community residence.

The objective must be seen as providing living resources of maximum benefit to the retarded person and in no sense preserving the geographically isolated, segregative, mass-care custodial practices of the comprehensive institutional hospital model. The transition will take time and must not be seen as reducing either public responsibility or public cost. Providing for both short and long-term service support, as needed, in community settings is an absolute precondition to the physical movement of present populations out of the centralized residential institutions.

• Using available legislation, the Federal Government and the States must develop long-range programs so coordinated as to *assure mentally retarded persons an increasing range of choices as to where they shall live.* The choices may vary from independent living to fully protected care, and should be responsive to consumer demand. (See Role of Government, Chapter 9.)

• Coordinated with residential alternatives in the local community, there must be developed appropriate, adequate *services essential to help retarded persons remain in homes of their own choice*, including living with their own families, with friends, or by themselves.

Crucial to the success of the retarded person living in the community are (1) the appropriateness of the living setting and its management to the person's attained independence; (2) the availability and accessibility of an array of supportive and developmental services which will enable him to function at present levels and develop to higher levels of competency; (3) the climate of acceptance in the community and its tolerance to the differences presented by retarded citizens in appearance and behavior, especially by those of moderate to profound impairment.

• *Restrictive building and safety codes and zoning ordinances must be modified* to recognize the degrees of independence and responsibility of retarded persons living in the community.

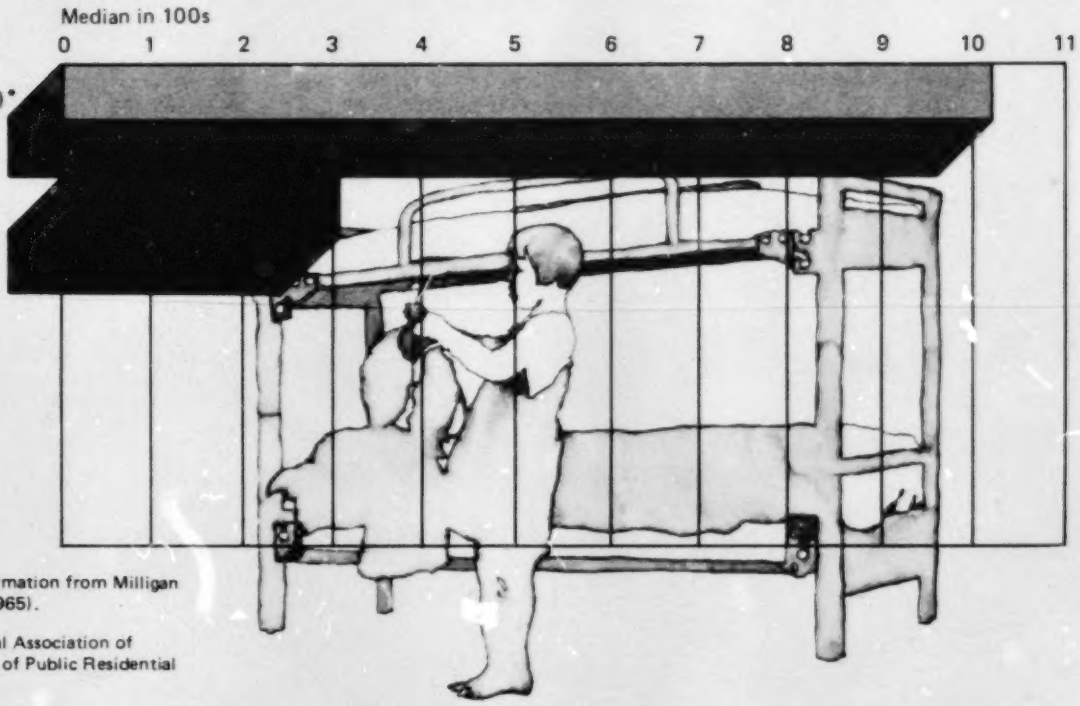
The designation "nursing home" by regulation and monitoring should be limited to those facilities actually providing medically directed nursing care to persons of limited self-protective and self-supportive capacity. The great majority of retarded children and adults require only the normal medical services of the general population. Individuals may be retarded in varying degrees and with varying capability of handling themselves appropriately in case of fire or other emergency. The overwhelming majority of retarded children and adults can learn to carry out the normal means of evacuating a building quickly or to perform others safety precautions. The need for "Nursing Homes" by retarded children and adults living in the community is limited to the small minority who require 24-hour nursing care of a medical nature. Insurance regulation should be modified to recognize the conditions of actual risk attendant on occupancy of dwellings by trained and educated persons who may be mentally retarded. Public information and education programs should be developed to prevent the misapplication of either building regulations or zoning ordinances in ways which are discriminatory toward mentally retarded persons living in the community.

The designation "family" residence in zoning and building codes should be broadened to include any group of people living together in the manner of a family regardless of consanguinity or legal relationships or absence thereof. This is essential for the establishment of group homes for retarded citizens in which the normal socialization of family life is shared.

• *Central, comprehensive, publicly supported institutions for mentally retarded persons must undergo an orderly process of change* from their traditional role as long-term, all-purpose, high-capacity, and self-contained organizations to that of care and treatment facilities for specific purposes, with capacity governed by purpose.

There will continue to be a need for the management of some problems on a regional or statewide basis by an organization which performs an integrating role in overall service delivery. For example, a resource center might offer special services, including complex differential diagnosis, management of acute or profound problems, treatment of complicating physical conditions, special training programs and research, and those meeting emergency needs. Emphasis should be on short-range goals. Due consideration should be given to whether these or other appropriate functions can be effectively carried out in the geographical location or in the existing physical structures of present institutions. Neither prior investment nor local economic or political interests should be allowed to perpetuate obsolete, substandard, or inappropriate residential institutions.

Newer and Older Residential Facilities By Rated Bed Capacities



*Based on information from Milligan and Nisonger (1965).

Source: National Association of Superintendents of Public Residential Facilities.

Federal and State legislation and regulation should tie any public funds to demonstrated achievement in the planned development and fulfillment of the appropriate purposes of such central residential settings as may be retained, as well as to the demonstrated quality of their assigned services. It should be emphasized that most of the institutions designed and built prior to 1970 will have very little role in the complex of services for mentally retarded persons in the next century.

- *States and communities should utilize technical assistance, such as environmental consultant services,* involving functional designing principles and flexible design models, for both community and central residential settings for mentally retarded persons.

Environmental design includes not only structural features of buildings, but all external and internal features which have impact on retarded persons, and which foster the most beneficial life for the residents, both presently and in the future evolution of supportive programs.

- *Comprehensive review and continued research* should be conducted on the effects of all types of residential service on the development of retarded persons with varying impairments.

Objective V: *Maintenance by all serving agencies of standards of quality and accountability acceptable to the community and to the individual mentally retarded persons being served.*

- *A basic code of uniform standards of service for mentally retarded persons should be adopted* by Federal departments serving mentally retarded persons, and by the States. The code should consist of fundamental principles directed toward service outcomes, rather than specific and detailed procedures. Sub-

stantial observance of these standards must represent a condition for any public financial support for delivery of such services. Waivers should be granted only on specific justification provided by law and regulation. There must be legal, administrative, and budgetary provision for enforcement of these standards, and reasonable but limited time for existing facilities to demonstrate compliance.

At the present time a number of systems of standards are in existence or in the process of development. They fall into two groups: (1) those involved in licensure which are designed primarily to provide for protection of life, health and safety: for facilities serving the retarded it is important that these be realistic in relation to actual hazard, not unduly overprotective and not merely extensions of stndards for medical facilities or schools; (2) those regulating the quality of service: it is of fundamental concern that these be based on *service outcomes in relation to objectives*, not limited to matters of organization, staffing and management in terms of arbitrary structural models.

Currently, there exist the ICF Standards embodied in Title XX of the Social Security Act; the sets of standards for residential and for community facilities utilized by the Accreditation Council for Facilities for the Mentally Retarded (AC FMR) of the Joint Council for Accreditation of Hospitals; several UAF-sponsored instruments such as the PASS System at Syracuse University and the Alert System being developed by the University of Kansas. There is perhaps some danger of confusion in the proliferation of evaluation standards, each seeking to be a universal instrument, but greater danger in the evolution of standards, which become bureaucratically cumbersome, inflexible, and an impediment to effective service development.

The recommendation of a "basic core of uniform standards" envisions an instrument which concentrates on agreed fundamental criteria of quality operation and performance rather than on the specific means by which they are met or the instruments by which they are assessed. *Flexibility in application, progressive development and novelty in service delivery, and responsiveness to local demand are essential in the prevention of smothering bureaucratic regulation.*

- A workable system for the reporting, storing, codifying, analysis, evaluation, and dissemination of *information on service delivery* to mentally retarded persons must be designed and put into operation at the earliest possible time. The resulting information should be disseminated in summary form to the public at large, and regularly updated.

Such a system must be Federally established, involving all departments and agencies serving the retarded, and should have satellite counterparts in each State. To be effective, this system must derive data from persons served but must not include a register of individual persons or in any way violate the principles of privacy and confidentiality of personal information.

Data to be included are:

•• identification of service entity;

•• demand for service, by classification;

•• service objectives;

•• characteristics of consumers of service;

•• service provision;

•• achievement or non-achievement of service objectives;

•• all costs attendant on the effort.

Such a reporting system should be designed for use both as a method of monitoring service delivery and as a source of information on the extent, nature, and cost-effectiveness of services for the mentally retarded. The need for this statistical reporting service is heavily reinforced by reports from the States which reveal that knowledge about emerging directions in programming for the retarded across the country is woefully lacking. One can find little excuse in this day of electronic information storage, analysis and retrieval, for the failure of such a system to be developed.

The issue of a "registry" of individuals and their service histories must be resolved by other means than national or even state level data banks. Arguments favoring centralized, cumulative case records usually have reference to those persons whose mental retardation is substantial and is expected to be a life-long condition requiring a continuum of successive service modes. The great majority of those identified as retarded, however, are of mild degree and temporarily classified status. For them, cumulative records may prove a hazard rather than a benefit, just as public labeling is likely to do.

The alternative and socially preferable procedure is to emphasize the accessibility of services when, as, and if the individual needs them, with complete freedom from service surveillance or stigmatizing record when the individual has no active need for intervention. Records will, of course, be kept in the private files of service providers, available only on a personal release basis.

• In order to effect quality control, Federal departments serving the mentally retarded should put into effect a *financial reward and penalty system* applicable to all formula and discretionary grant funds to the States. This system should be responsive to proven ability or failure to provide needed services, maintain quality standards or meet reporting obligations. The system should be based on small but significant increments or decrements in financial support for achievements of or failure to meet obligations.

• Every Federal, State, and local program serving mentally retarded persons should be required to make regular evaluations and issue public reports on the *outcomes of service* in relation to financial or social costs. The findings should be based on appraisal of services made by mentally retarded consumers or their personal representatives, by the serving agencies, and by independent judges or evaluating agencies.

Objective VI: *Adequate research maintenance and utilization and manpower development to implement the most effective service delivery possible.* Specifically, these objectives include (1) services and systems research; (2) the targeting of prime need areas of basic and applied research; (3) the translation of research findings into training and practice in service delivery (4) the preparation through initial, supplementary or continuing education of qualified manpower to meet the full spectrum of needs in the field of mental retardation.

• Development of a *national study and reference center* on mental retardation and related matters. This center would serve two primary purposes: (a) as a focus of continuous study of the large-scale issues of principle and policy, linking all aspects of the problem toward the achievement of national goals; and (b) as a forum for the continuing intercommunication of all organizations, agencies, groups, and individuals in any way connected with the prevention of retardation or the delivery of services to mentally retarded citizens. Such an organization would be private, non-profit, and independent of unilateral control by any of the specialized groups it might involve.

On the American scene today there are a multitude of groups—governmental, professional, academic, public service, volunteer, proprietary, consumer advocacy, and representing various other special interests—all involving activities, operations, or concerns affecting mentally retarded citizens. Their spheres of activity intersect in varying degrees, sometimes very effectively but frequently to a minimum and at times not at all. There is no one forum or arena in which they all meet on common ground or harness their efforts on a basis of mutual understanding. There is need for a means of intercommunication without which the contributions of different interests to the definition and achievement of common objectives tend to be divergent, conflicting, mutually frustrating, or irrelevant. Controls by centers of power, governmental or otherwise, then lack the counter-balancing influence of general consensus deriving from the many sources of interest and concern.

The proposed organization would be assured independent status by its reliance on a fully representative board and on well-distributed and equitable funding obligations of participant groups, contract fees, and special endowments. Under no circumstance should it be a de facto arm of government or the special preserve of any single organization or selective coalition.

The first requisite step would be the formation of a representative planning group to make a study of feasibility, develop an initial format for organization and function, and insure an adequate basis of supporting interest.

• Active and continuing consolidation, field testing, coordination, and *transfer of research findings* on mental retardation to serving agencies and systems, training institutions, and other research centers should be systematically developed. This system should provide, through HEW, regional Offices, and other channels, continuing technical assistance to State and local serving agencies and training centers to assure the translation of new knowledge into manpower preparation, pilot service innovations, and long range service development.

• The *planning of manpower needs and development* should be addressed immediately by HEW in collaboration with the States. Such a plan should (1) develop the means for long-range determination of manpower requirements under the existing state of the art of service delivery; (2) develop and promulgate long-range manpower development plans for the nation, including provision for new types of manpower as projected programs and future needs determine them; (3) provide for regular modification of these plans to incorporate new knowledge and technical developments; and (4) assure an adequate present and future supply of trained serving agents to meet requirements of adequate and humane serving systems.

• In order to carry out the necessary training and preparation of manpower to meet the needs in all parts of the country, HEW should develop a comprehensive program involving the full resources of higher education. Such *a program should be designed to provide adequate manpower development* to meet all the needs of mental retardation in each part of the United States on a long-range basis. It should use all feasible means of developing and utilizing the training resources in the educational institutions of each State and area through consortia, out-reach programs, in-service extensions, or other means in addition to traditional academic degree programs. Universities, public and private colleges, community and junior colleges should all be involved in these efforts, with the role of leadership and coordination designated on a basis appropriate to the characteristics and resources of each area. The scope of manpower concerns falling within this program would be limited only by relevance to the issue of mental retardation and related disabilities. It would range from workshops for the orientation and training of volunteer personnel, through the training of direct care personnel, to professional training of the most advanced nature for administration, research, teaching, and professional service functions.

For some years the Federal Government has provided support for manpower development in the national interest. The focus of such support has fluctuated and shifted with changing national needs. At the present time, major program supports in higher education relating to mental retardation include the University Affiliated Facilities, the Mental Retardation Research Centers, the Rehabilitation Research and Training Centers, and the traineeship program of the Bureau for Education of the Handicapped. In addition, various schools and disciplines are training an increasing number of professional people who will utilize their training in mental retardation settings. However, these programs fall far short of the total need, and each is confronting problems of organization, mission, funding, and coordination. The role of higher education is itself undergoing significant changes, with a tendency which will most likely become more pronounced during coming decades to extend its efforts to new and wider constituencies in the community and to relate its efforts more directly to social need.

The greatest manpower need in mental retardation is now, and will continue to be at the levels of direct service contact. New types of occupations related to service delivery will appear as the shift to community-based programming advances. It is highly opportune for HEW to exercise initiative in exploring with leaders in higher education together with leaders in the field of retardation, both providers and consumers, and Federal and State agency leadership, the full scope of MR manpower development. The 1975 Developmental Disabilities Act Amendments take certain forward steps in this direction. A special task force is exploring the future role and development of the UAF concept. The problem is far broader than this, however, and should be examined on a fully comprehensive basis.

• A significantly expanded effort should be made to *involve large numbers of volunteers* in many areas of service delivery. Volunteers should be recruited particularly among those portions of the population outside the work force, such as older Americans who can be expected to increase in numbers significantly in the next quarter-century. Volunteer services can be developed both to complement and to supplement professional services.

Chapter 7

Mental Retardation As An International Problem

"It would be a serious error to confine our view of the 'century of decision' in mental retardation to the efforts of the United States alone, disregarding existing and potential relationships with other countries in the resolution of these universal problems.

Advances both in scientific knowledge of mental retardation and in ways of helping people who are mentally retarded have been international in nature.

The earliest educational efforts to teach the retarded were in France, Switzerland, Germany, Austria, the Scandinavian countries, Japan, and the United States. Scientific discoveries of major importance concerning causes and prevention of retardation were made in all the major countries of the world. The development of sheltered workshops owes much to Holland, comprehensive community-based services to Denmark, "normalization" as a practical system of developmental assistance to Sweden, teacher training for special educators to the United States. All of these steps forward have been shared among the nations.

Mental retardation knows no national boundaries in its occurrence or in its impact on the human condition. It rises above political, economic, and cultural differences, although cultural values are clearly reflected in systems of care and patterns of social acceptance, and the incidence is a reflection of local conditions of health and social well-being. As in other human affairs, countries may be more or less advanced in their management of the problem, but there are strong currents which foster intercommunication and mutual aid.

Simultaneously in most advanced countries, movement in science, professional management, and parent volunteer organization took place following World War II. The United States learned much from other countries and in turn has given much. It is surprising to many Americans to discover that some countries are far in advance of the United States in movement toward the goals for this century projected in this report.

Consequently, it would be a serious error to confine our view of the "century of decision" in mental retardation to the efforts of the United States alone, disregarding existing and potential relationships with other countries in the resolution of these universal problems.

The goal of our international concern is:

The attainment of a high and stable level of international relations in the cooperative resolution of the universal human problems of preventing and ameliorating mental retardation.

The following objectives to be pursued in the attainment of the overall goal may be furthered by a variety of means, some of which are stated below.

UNITED NATIONS
GENERAL ASSEMBLY

Declaration on the Rights of Mentally Retarded Persons

Adopted 20 December 1971

The General Assembly,

Mindful of the pledge of the States Members of the United Nations under the Charter to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights,[1] the Declaration of the Rights of the Child[2] and the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and of other organizations concerned,

Emphasizing that the Declaration on Social Progress and Development[3] has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of assisting mentally retarded persons to develop their abilities in various fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Mentally Retarded Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.

2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.

3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.

4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.

6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.

7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

2027th plenary meeting,
20 December 1971.

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[1] Resolution 2200 A (XXI).
[2] Resolution 1386 (XIV).
[3] Resolution 2542 (XXIV).

Objective I: *Full and continued participation of United States governmental and non-governmental agencies and organizations in international bodies concerned with mental retardation.*

• *Many United Nations* agencies conduct activities relating to mental retardation, and the UN General Assembly itself adopted a Declaration of Rights of the Mentally Handicapped in 1971, with United States support. The United States, under State Department leadership, should participate actively in furthering such efforts.

Active interest in problems of mental retardation is maintained by the Rehabilitation Section of the ECOSOC, by the World Health Organization, UNESCO, ILO, and UNICEF.

• The Department of State and other agencies of Government should maintain active interest and participation in the *Inter-American Children's Institute* of the Organization of American States, and support the involvement of U.S. citizens and groups in the activities of this organization related to mental retardation.

• The Department of State, HEW, PCMR, and other agencies of government should encourage and support membership and participation of United States citizens and groups in such *non-governmental organizations* as the International League of Societies for the Mentally Handicapped and the International Association for the Scientific Study of Mental Deficiency.

Objective II: *International assistance programs in mental retardation, designed to utilize the developed resources of any country in the organization and operation of mental retardation programs, techniques and personnel training in other countries.* The following are some of the channels through which this can be accomplished:

• The activities of *UN Agencies* as the intermediaries for requested assistance.

• The *AID programs* of the United States.

• Such programs as *"Partners of the Americas"* PREP program, involving relationships between North American universities and those of Latin America; and other relationships fostered by the Organization of American States.

• The use of blocks of *Fulbright-Hays grants* focused on the field of mental retardation.

• Short-term intensive *workshops for personnel training.*

• Short-term intensive *workshops on organizational and operational techniques* in mental retardation programs.

• International *exchange of films*, film-strips, and slides with appropriately translated or subtitled explanatory text.

• The continued use of *PL-480 counterpart funds* as authorized by Congress on mental retardation projects by agencies of HEW.

Objective III: *Development and maintenance as basic policy of the United States of the international exchange of knowledge and information on all aspects of mental retardation.*

The following means are proposed to achieve this objective:

• Participate in the conduct and the reporting of *international scientific seminars* and conferences sponsored by international organizations, universities, scientific and professional associations, and the like.

Such meetings should emphasize the advancement of knowledge leading to improved means of prevention; technology in all areas of understanding and ameliorating the consequences of mental retardation.

• Encourage and support the *exchange of visiting groups* of professionals, students, and citizens for better understanding of programs and facilities for retarded persons in various countries.

• Development of systematic means, under the leadership of the Library of Congress, for the *exchange and translation of significant world literature* in the field of mental retardation.

• Development of and support for an *international information system* in mental retardation.

Efforts have begun on a small scale through the Center for Documentation and Information on Problems of Subnormality, in San Sebastian, Spain; and in the development of a more systematic international information storage and retrieval system at the University of Pittsburgh.

- The *International Directory* of Mental Retardation Organizations and Activities published as a joint venture of PCMR and the International League of Societies for the Mentally Handicapped. This needs to be maintained in a current state by periodic revision.

- Facilitation by the Department of State, in cooperation with HEW, PCMR, and other government agencies and professional organizations, of international research projects and seminars on significant problems in mental retardation, with the provision of *supporting funds for organization and travel.*

Examples of this are the project in autism and retardation in Uruguay; seminars on neurological problems and on nutrition in Mexico City; symposia on guardianship, sexuality, residential care, recreation and leisure, and other topics sponsored by the International League; seminars on biomedical and genetic problems sponsored by groups of scientists; Congresses sponsored by the International League and by the International Association for Scientific Study of Mental Deficiency, and many others. In general, for the most productive outcomes, face-to-face meetings of experts and concerned citizens across international lines are by far the best means of stimulating knowledge and exchanging information on a current basis.

Kevin Packard and Bart Laveck

When the two boys came as 3-year-olds to the Happy Learners Center, no one dreamed they would eventually be admitted to a regular public school kindergarten class. Now, at 5½, they're ready. Arrangements for enrollment have been made. The parents, and many who worked with them, harbor a quiet hope that their developmental climb will continue in the public school system.

The Happy Learners Center is one of a series of preschools within a five county region which integrate a few handicapped children into each of their regular programs. (This plan of integration was developed by the region's community service agency with the help of a grant from the U.S. Bureau of Education for the Handicapped.) The rationale for doing this is based upon the idea that children learn a great deal from other children. It is believed that handicapped children like Kevin and Batt, two very different little boys, can—with proper resource teacher support—develop better in such a setting.

Kevin came to Happy Learners by way of Headstart Program and a local children's rehabilitation institute. His condition was described broadly as "a general failure to thrive." He was thin, withdrawn, unable to walk or talk, and he failed to respond to all family efforts to toilet train him. He didn't like to be touched. When someone held him, he became stiff. The parents were frustrated and impatient with his lack of development.

"Children learn a great deal from other children."

Bart, a child with Down's syndrome, was referred by the local association for retarded citizens shortly after his family moved into the community. He was an only child who seemed happy and secure enough, but he showed signs of developmental delay characteristic of the syndrome.

Each of the boys had a daily one-half hour period working on individualized objectives with a resource teacher. The rest of the time was spent in regular programs. Simultaneously, the resource teacher worked with the parents, aiding the families to continue working on simple specific objectives at home.

At first, Kevin responded mostly to the daily individualized program with his resource teacher. According to her, his earliest response was in learning to move.

"Kevin was helped to crawl up and down steps. This discovery seemed to please him, and he began to show an eagerness to try other things. Next, he stood up, holding a chair and pushing it. Then he used a plastic ball bat to steady himself. After that, he took off! Walking became fun for him, and it opened the way for the next thing that we worked on, which was a game of touching other children and letting himself be touched."

Bart's early learning experiences were quite different from Kevin's.

"Although Bart benefitted from our individualized period, he liked being with the rest of the children. In group singing, finger plays and games, he began to mimic the other children. This kind of 'modeling' was encouraged."

The remarkable thing in both Kevin's and Bart's cases is that other children held no prejudice for the delays they showed. When children asked about them, they received simple, honest explanations from all the teachers. When their questions were answered, they became more friendly and tolerant of those who were slower than they.

Now, at 5½, the boys have mastered toilet training and self-help skills. Both can print their first and last names. They can count to 20. They know their addresses and telephone numbers. They can recite the alphabet. Kevin has become a more sociable person. Bart has achieved a remarkable increase in his attention span and can speak longer sentences, even though the muscular impediment to his speech is still apparent.

As Kevin and Bart approach their first day in kindergarten, their previous successes raise many new questions. Will the public school be able to produce the same type of resource teacher system? If Kevin and Bart had had programs of infant stimulation—as in-home trainers have now developed it—would they have been farther along, and more ready for public school? Will teacher prejudice arise against Bart—whose Down's syndrome is apparent—so they will be quicker to recommend placing him in the special education class where many other children with Down's syndrome are usually admitted? Will competition become so intense that Kevin may tend to withdraw? What will be the attitude of the public school administration? Will parent/teacher teaming remain as effective? What will happen when they move from this richly individualized but integrated preschool to a public school kindergarten?

Chapter 8

Public Attitudes

"The final phases of this 'century of decision' for those who are mentally retarded will depend on what image, in the end, is the guide to public action."

Public attitudes have always been crucial in determining the fate of American's retarded citizens. It has been paradoxical that in a country with such deep democratic traditions, embodied in a Constitution whose Bill of Rights is a model for mankind, segments of humanity could be forthrightly rejected. During the late 19th and early 20th centuries the public was persuaded by the eugenicists and certain directors of institutions and public officials that the "feebleminded" were helpless, hopeless, and too dangerous to be at large. As a result, treatment in isolated, custodial institutions became a predominant pattern.

Even while the negative image of the retarded was forming a hard knot in the public mind, however, older concepts were at work:

the parents of retarded children preferred, out of love, to keep them at home, even though in a back room;

judges were reluctant to commit for life persons whose only crime was to be thought capable of degeneracy and of reproducing their kind; and

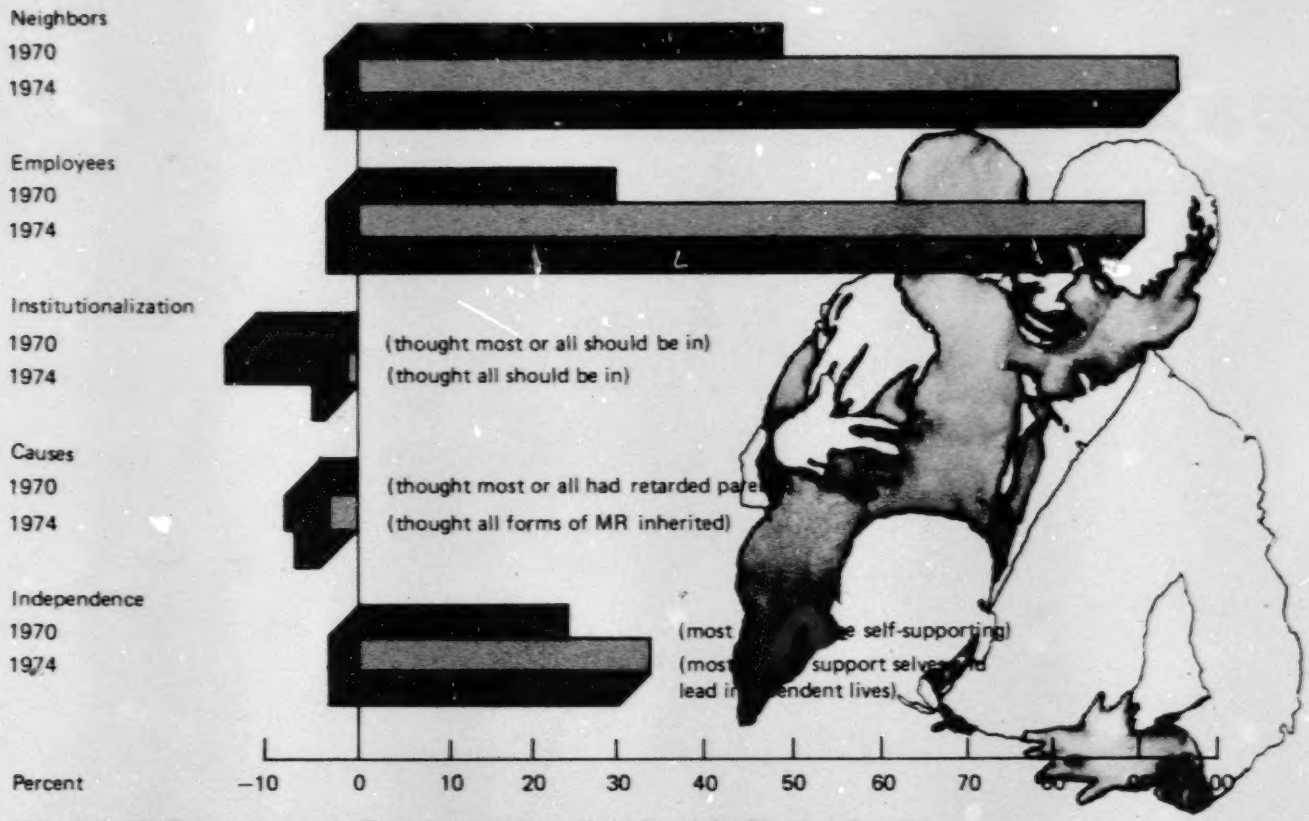
some educators were cautiously and hesitantly preserving an alternative of educational preparation for community life.

Perhaps the oldest image of the retarded person in the American mind is seen through the lens of a democratic ideal that says, "Misfortune does not make a person any the less my neighbor."

As a result of slow undercurrents of change erupting into intensive efforts by newly organized parent groups, by professional associations and by government, the 1950s saw growing awareness that retarded people have underdeveloped potential far greater than had been recognized, that they do not present the serious danger of criminal viciousness or hereditary taint that the preceding generation had learned to believe. Out of this awakening grew support for greatly expanded programs of education, vocational and other services that would, if they were sustained, enable most retarded persons to function in the community. This beginning of a new public attitude laid the groundwork, not only for community services, but in time for the movement toward full citizenship based on law and constitutional right, through class action suits and corrective legislation.

Yet the task of public enlightenment is far from finished. Old fears and prejudices die slowly; they remain buried under the surface of currently publicized opinions, even though, at rock-bottom, the solid core of a democratic and humanitarian tradition remains. The negative image of the "menacing moron" was covered over by the 1950 image of the "unfortunate child in the shadows" who, despite his life-

Improvement in Attitudes Toward Retarded Persons



1970: From CEC Research Monograph, "Public Awareness About Mental Retardation," by Henry Gottwald.

1974: From Gallup Report prepared for President's Committee on Mental Retardation

long disability, nevertheless could be helped. We respond to that warm appeal for nurturant care and charity.

Now we attempt to replace the image of the "eternal child" with the image of the adult citizen, not so appealing, and not so easily kept on the charitable fringe of life. Now he becomes one of us, a member of our common community, with rights the same as ours, despite his differences in capability or appearance. This is an image which is, so far, only a thin veneer. It has not yet become deeply implanted in the minds and hearts of more than a handful of people.

In these days of economic distress and social uncertainty, the deeper layers of negative emotional response to mental retardation are easily exposed once again. Beneath the acceptance of the harmless child lies still the menace of a threatening adult whose difference from us we view with exaggerated alarm and whose presence in the community makes us uncomfortable, especially if we see the retarded adult as a threat to the wage structure, or to property values.

As we look ahead to the end of this century and the beginning of a new one, the need to sustain and deepen public understanding is urgent. The final phases of this "century of decision" for

those who are mentally retarded will depend on what *image*, in the end, is the guide to public action. If understanding, which present knowledge can give us, is deepened to an emotional linkage with the humanitarian and democratic roots of our national heritage, there is real hope for mentally retarded Americans. Without that linkage, their future may be very dark, as they are once more rejected—to what fate, then?

The task of promoting public acceptance of retarded persons as citizens can not be undertaken in a vacuum. It is closely related to the development of a total social climate favorable to all the kinds of human diversity that exist in our society. How difficult that task will be depends greatly on the resolution of two major public concerns of the immediate present: the threat of continuing or recurring economic depression with its complication of threatened, long-term shortages; and the racial and ethnic tensions, so highly volatile if distress deepens. If, as our advisors on the future tell us, these problems can be surmounted within reasonable time, then the climate for our task will be greatly improved. If these sources of stress are prolonged, it will require an extraordinary effort to achieve our goals.

Looking at the future in this manner, the Committee can state its goal for public attitudes quite simply:

To achieve a firm and deep public acceptance of mentally retarded persons as members in common of the social community and as citizens in their own right.

The approach to this goal lies in three major objectives.

Objective I: *Advancement of those values which emphasize the worth of every human being without regard to his material possessions, his job status, his productivity, his IQ, or his beauty, and which recognize the importance of diversity and the right to be different.*

"Unless we devise ways of accelerating processes of value change so as to assure that love, work, and play can afford all people self-validation, the fate of the retarded may presage the fate of us all. Material basic sufficiency in the outer world could be matched by character destitution in the inner world. We could even wind up with inescapable bitterness of having satisfied all our basic wishes without ever having learned how to wish for all our basic satisfactions.

"But if we negotiate these rapids successfully, the future holds possibilities of fulfillment for all people of a quality unmatched by that in the past. Each person, no matter what his endowment or handicap, could be fostered in realizing his potential. And each person would be able to advance with the awareness that his satisfactions amplified rather than diminished those of others."
Gorney

In the above statement by one of the "futurists," (see Chapter 2) Dr. Gorney strikingly states the impact on retarded people of our society's values, human or material. Since our behavior flows from our values, we look first at a few possible ways to promote appreciation for those values which emphasize the worth of every human being.

- Appropriate attention must be given to the areas of human values, of working with minority cultures, and of dealing with handicaps in the *training of all new teachers*, plus in-service training and the furnishing of curriculum aids in these areas for all present teachers.

EDUCATION should set as a major goal the development of individuals who recognize the right to be different, and can work cooperatively with persons of widely varying abilities and backgrounds.

The need for such an effort is immediate as well as long-range. Thousands of handicapped children will be entering school in the next few years as a result of court decisions and legislation requiring a "zero-reject" policy. Children already in school need to be prepared for this influx. Epithets of "dummy," "retard," and "moron" can create emotional wounds that never fully heal.

The teacher sets the pattern of behavior for the children, whether consciously or unconsciously. Today we have many teachers dedicated to bringing out the potential of all their pupils, whether it is great or small; they do so in loving, supportive ways. Some, however, radiate an intellectual snobbery toward the less capable students and to those who work with them. Other children sense this, and reflect it in their more overt behavior, name-calling, teasing, exclusion.

If the teachers are to foster understanding of human values among children, including those of minority groups, they need first to acquire a deep awareness of such values themselves, and then tools and materials to assist them in transmitting these values. They need also a basic understanding of the nature of mental retardation, and a command of educational methods which have proved successful with retarded children. Such knowledge will enable them to deal with these children in a positive, confident way, rather than with fear of failure.

- *All students* during the period of elementary and secondary education should be familiarized with the nature of handicapping conditions, both physical and mental, in the context of human values expected in the teaching environment previously discussed.

This will be enhanced by the increased presence of mentally retarded children in the regular school environment if the present trend toward "mainstreaming" of the retarded is successfully developed. One of the necessary ingredients in successful mainstreaming, however, is the cultivation of a receptive and understanding climate which in turn generates positive attitudes and behavior on the part of the handicapped children. It is a cyclical process which can spiral upward or downward.

Implementation of such a value-oriented approach to human relations in the education of children must apply at all levels:

- The *Federal Government* must continue to move forward under the authority of Part D of the Education of the Handicapped Act, which provides not only for the training of special education personnel but also for the training of regular teachers in knowledge and sensitivity to the needs of the handicapped.

- The States should make training in human values and working with the handicapped a requirement in the *certification* of all teachers, not only of special education teachers.

- *Schools of Education* should develop units on human values and teaching the handicapped as part of the curriculum for all students.

- *Courses on mental retardation* and related disabilities should be included in the curricula of all students of medicine, dentistry, nursing, law and law enforcement, education, religion, psychology, social work, and any other field in which professional practice involves contact with developmentally impaired persons.

More easily reached than the general public are such specialized learning groups, preparing for professions which bear ultimately on the problems of handicapping conditions and handicapped persons. It is essential to bring the subject of mental retardation within their awareness at the time of training.

- The continuation and expansion of the "*education for parenthood*" program is essential, with inclusion of material on mental retardation.

With the present trend in the sexual mores of teenagers, the possibilities of mental retardation in children resulting from early pregnancies or pregnancies in which the mother has VD should be fully known.

At the same time, teenagers are the most ready of all age groups to adopt positive and supportive attitudes towards handicapped people, as illustrated by the striking growth and activity of Youth NARC and similar movements. This should be fostered and illuminated by exposure to the best available information on mental retardation and associated human relations.

- Civic organizations in each community should search for creative ways to *enhance community regard* for the teacher, social workers, recreation leaders, employment counselors, residential aides, and all others who provide supportive service to retarded persons.

RECOGNITION in some form should be given to teachers and others who work with and for retarded persons. A society that bestows innumerable honors on athletes, entertainers, authors, and other individual achievers surely can find ways of according status to those groups dedicated to helping others achieve their potential.

- ACTION, the National Center for Voluntary Action, and corresponding groups in every community should *intensify the enrollment of volunteers* in activities involving direct contact with retarded persons. In some cases, monetary incentives at least to cover expenses should be used to compensate, as in the Foster Grandparents program; in others, tax credits; and in still others, academic credit in field assignments.

VOLUNTARISM is a means of diffusing the kinds of human values that are favorable to retarded persons. It is of course beneficial in terms of what volunteers can do for retarded children and adults, but what may be overlooked is the profound effect the contact with retarded persons can have on the volunteers. There is no better way to acquire appreciation for the human qualities of those people who happen to be retarded than to spend time with them, in a group home, on a bowling outing, in a Special Olympics meet.

An important by-product of voluntarism is the stimulation of volunteers to undertake training to become involved occupationally in work with mentally handicapped people. Professional directors of volunteers should be on the alert to identify good prospects for professional or subprofessional training for the multitude of service positions needed, and should help them get into the appropriate training programs.

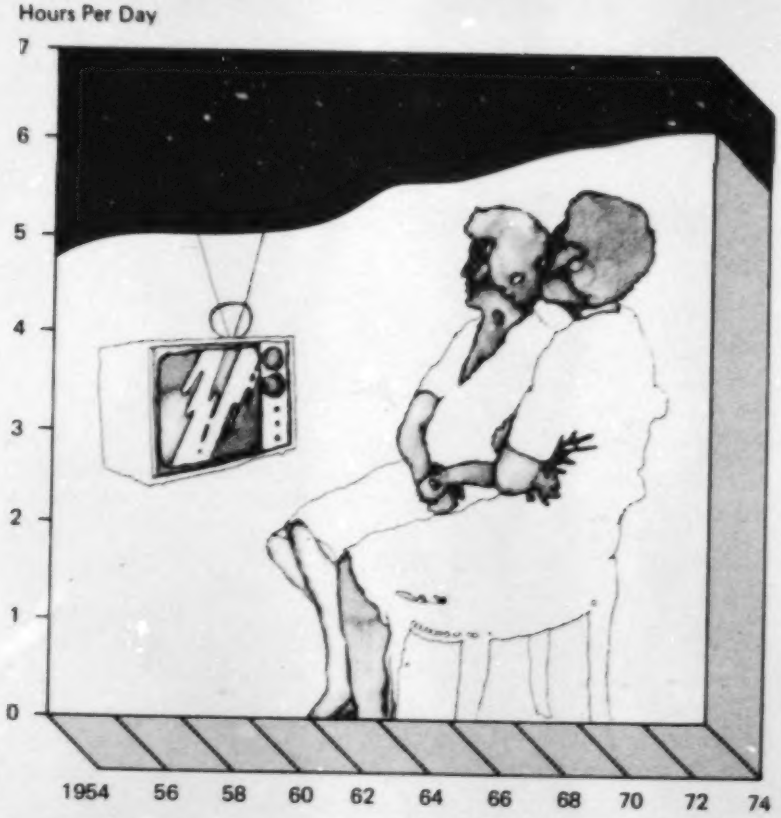
Objective II: ***A pervasive feeling of confidence that there will be a sufficiency of jobs, energy, and other material goods to support a realistic surge toward humanized values.***

An atmosphere of confidence in the future is the best climate for the solution of human problems we face now. In that atmosphere, retarded and other handicapped persons will be regarded not as usurping competitors or as a burden or threat, but as needed participants in society, in the work force and in other community activity. Under those circumstances, the mass of citizens can and will support the services that handicapped persons need in order to achieve some degree of independence.

The testimony of the futurists consulted by PCMR emphasized an optimistic view of the future despite the multiplicity of difficult problems to be solved.

Those who look through the "right" end of the telescope are confident that by the year 2000 we will have

Average Hours of Household TV Usage Per Day



Source: A. C. Nielsen Co.

the options of ending poverty as we know it today, and providing everyone the opportunity of employment or a meaningful equivalent.

Those who focus on the short range can see only laid-off workers, energy shortages, and prices outstripping purchasing power. In this world view, based on the assumption of perpetual scarcity, attitudes toward retarded persons are likely to be negative: "We don't have enough to go around, why should we support those who don't produce?" Carried to their extreme, these expressions turn into proposals for Hitlerian legisation, such as the so-called "death with dignity" bill introduced in the Florida State Senate. This bill would permit the withholding of medical services and medicine from retarded persons in State institutions, so that those with Down's syndrome, for example, would succumb to pneumonia, to which they are especially vulnerable.

• Advocates for those who are retarded must *cooperate vigorously in national and local efforts to achieve a society of sufficiency*, and work for a climate of public confidence that such a society is on the way.

Men are not helpless. They *can* influence their future. This Committee is convinced that the American nation and its world partners have the power to shape a 21st century of adequacy for all. In such an era, no one need begrudge the retarded person his place in the economic sun. While there will always be competition for tax dollars and private funding of social services—and indeed it is healthy that there should be such testing of programs' worth—the economic base will be adequate for effective developmental assistance to retarded Americans. And when such assistance equips them to go into the job market, opening of opportunities for them will not mean a denial to others.

As more and more retarded people enter the world of work, their fellow employees will acquire attitudes toward them based on actual experience rather than on fear or ignorance. The retarded persons themselves will develop an enhanced self-image which in turn reinforces their ability to be self-sufficient.

But these rosy hopes may be dashed, or at least delayed, if present economic uncertainties unduly influence public estimates of the future. It is in the context of such estimates that people will form their attitudes about the retarded segment of the population.

Yet, at its roots, the American philosophy has never been a "lifeboat" ethic. It has rather been the ethic of people living on the frontier. Whether the frontier is of the natural wilderness or of the social milieu —we share what we have with those in need.

The above recommendation may seem elusive—it certainly does not lend itself to tracking in a "management by objectives" system—but it must be a philosophic underpinning for the public awareness program that is needed.

Objective III: *Use of changing trends and techniques in communications to promote (a) greater understanding of and appreciation for handicapped persons as neighbors, fellow employees, and fellow citizens, and (b) understanding of the means of reducing the occurrence of mental retardation and other handicapping conditions.*

"We are faced with the emergence of a new and powerful set of technological capabilities, which, by its function as screen, channel, and 'multiplexer' of information, actually reshapes the information content and perception of society."
McHale

- A continuing program, substantial in size and high in quality, for *educating the general public via all communications media toward acceptance* of retarded and other handicapped persons must be sustained.

New trends in communications technology offer great potential for developing favorable public attitudes toward retarded people, but entail some problems. The flow of information will increase greatly in both speed and volume. With the increase will come many more opportunities to disseminate information about retardation. But at the receiving end of all those transmissions will still be the human brain, which can absorb only so much. Close attention will have to be paid to the quality of messages about mental retardation. This will call for a high degree of professionalism, tempered by a dedication that will remove the harsh edge of commercial slickness.

The following suggestions may be of possible use.

•• The *capabilities* of retarded persons, including those severely retarded, are known by too few people and should be emphasized.

•• The fact that all of us are *dependent* in many ways, and that all of us are "retarded" in some respects is worthy of attention.

•• Messages should be *reassuring*, allaying rather than creating fear with respect to the characteristics of retarded persons and the preventable causes of such handicapping conditions.

•• Television can have a favorable impact on attitudes simply by *including persons with handicaps* among groups in normal situations, without making a specific point about it. Their inclusion would condition audiences to accept handicapped persons as part of the pattern of everyday living. The recommendation applies to programs for all levels, from nursery school on, and to both commercial and entertainment as well as to news and documentary material.

•• In showing mentally handicapped persons, the actual variations of *physical characteristics* among them should be reflected. Most cannot be distinguished from "normal" people by appearance alone, so it is appropriate that such normally appearing individuals predominate in presentations to the public. But the small minority of mentally retarded persons who do not look "nice" should be included in our attempts to broaden tolerance of difference.

•• Opportunities should be sought for mentally retarded persons to act as their own *spokesmen* to the public. No third party can be as believable.

• A continuing program, substantial in size and high in quality, for *educating the public concerning the causes and means of prevention* of mental retardation is essential.

The approach to this aspect of the problem must be different from the approach to public acceptance. It should have the following characteristics:

•• *Information* should be accurate and up-to-date, avoiding exaggerated, premature or unconfirmed statements.

•• *Environmental hazards*, such as lead poisoning, should be presented in the context of community action and public policies.

•• *Hazards of pregnancy* should be presented in clear, straight-forward terms without scare-heads, and with clear information on good self-management and proper sources of professional help.

•• Emphasis should be placed on the *right of informed decision* in all matters involving choice of alternatives, regardless of controversy.

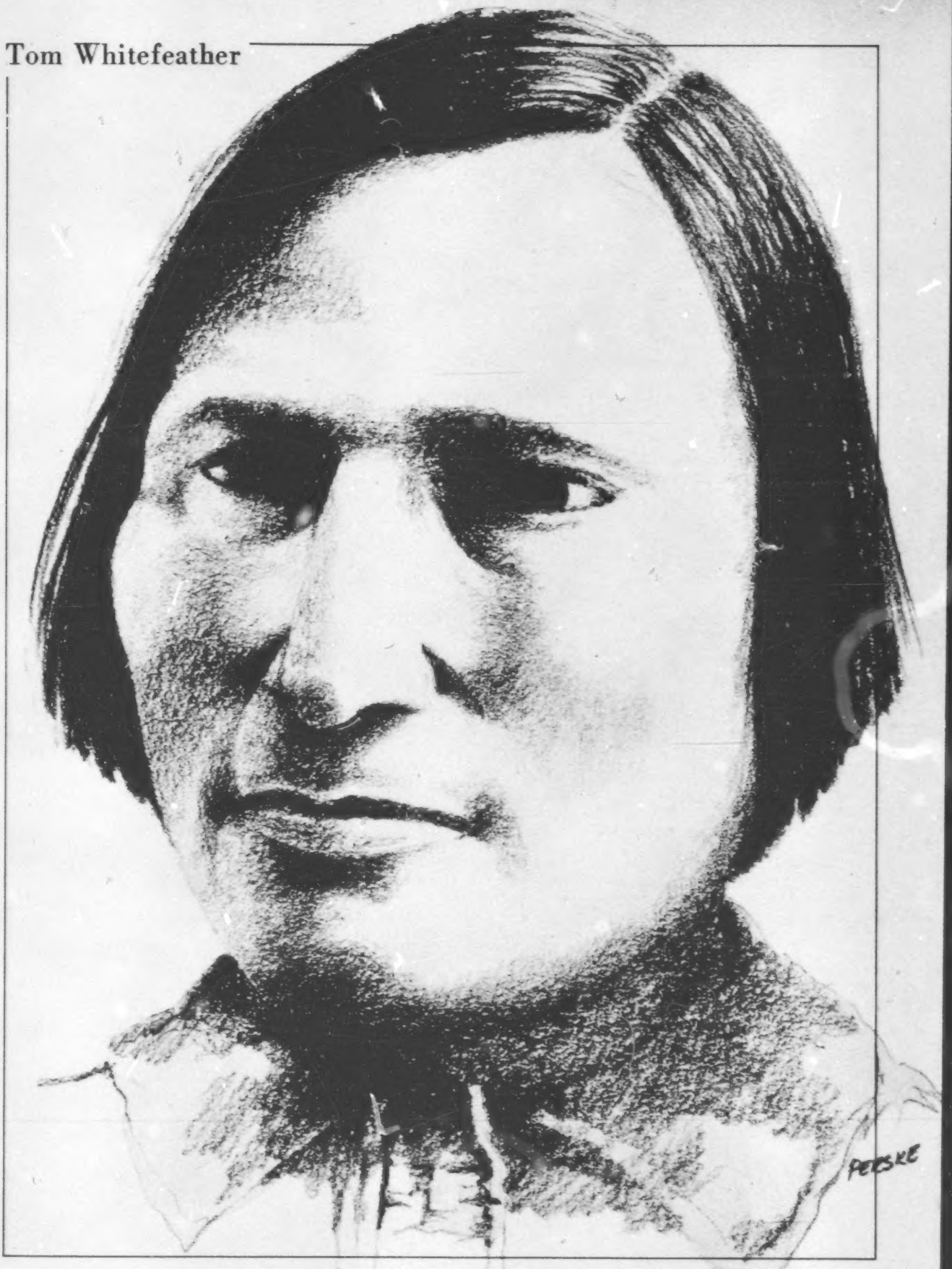
•• Sources of reliable information and professional counseling should always be emphasized.

• Every agency or organization concerned with mentally retarded people—national, State or local, public or private—must intensify its own informational efforts and *build a community understanding component into every operating program.*

The value of local initiative in public relations cannot be overstressed. Direct communication of information from and to people you know and trust is one of the most powerful vehicles for influencing attitudes.

The hope of realizing the goals of the President's Committee on Mental Retardation, as stated in the preceding chapters, rests in the end on the favorable development of public attitudes toward retarded persons. The image of the retarded person perceived as our neighbor and as a citizen among us—if this can prevail, then, indeed, it will be the Century of Decision on mental retardation.

Tom Whitefeather



"Both alternatives seemed fearful after living in Castle Rock State Home since he was 12."

He's 18, and he has a choice to make. One of the social workers carefully explained that he could return to the reservation and live with his sister's family, or move to Mountain City and live in a small group residence. Both alternatives seemed fearful after living in Castle Rock State Home since he was 12. He was no longer sure of himself as a Lakota Sioux. On the other hand, he wasn't completely comfortable in the white man's world.

Tom had been committed to the institution by the court, after being found guilty of breaking into a hardware store, his third offense. A social worker's report pointed out that both parents were alcoholic. A court-appointed psychologist testified that Tom was "functioning in the mild mental retardation range."

The transcripts of the case show that representatives of the tribal council had petitioned the court to order that he be sent back to the reservation in their official custody. They testified that the staff at the institution were neither familiar with, nor understood the cultural values of their tribe. The petition was denied.

When Tom Whitefeather first came to the institution, it was recorded that he "walks slow . . . Will not take care of his clothes and possessions, and for the most part is uncommunicative. When he does talk, he mumbles . . . . He cannot be depended upon to carry out any working task."

Later notations in the records show that Tom's early negative attitude began to fade. He profited from educational classes and vocational training. Also, he developed acceptable work habits in the institution's laundry.

In a recent interview, a member of the tribe gave an explanation of his early failure at institutional life.

"The white man's values are different from the Indian's. Members and families in the tribe may not show it outwardly, but they are a close-knit people. That's why most mentally retarded Indians should remain on the reservation. If they need help it will best be given by our own people."

The tribal member pointed out that once their highest values had to do with learning the world of nature. They had little need for competitive technocracy and the acquisition of many possessions like the white man, because the whole world was "always there and always available." It's not easy for the American Indian to solve the clash between his own and the white man's culture.

In an interview with the social worker responsible for placing Tom on the reservation or in Mountain City, it was learned that she had never been to the reservation, 120 miles away, and—to her best recollection—none of the staff had been there.

When the social worker carefully explained the choices he now can make, Tom sat silently, as if waiting for someone else to make the choice for him. This slow-moving, soft-talking young man with a record of personal development at Castle Rock State School is unable to verbalize the inner conflict—and maybe the wounds—he feels.

When he came, he was definitely a Lakota Sioux Indian. After six years away from the reservation, he wasn't sure. On the other hand, he heard that many persons in Mountain City were prejudiced against Indian Americans. Could he take that? Would he be able to get a job?

Tom is faced with the choice of entering one of two worlds that function differently and have little real understanding of each other. His inability to decide stems from his own confusion about himself, who he is and to whom he belongs.

Tom Whitefeather sits quietly while others are urging him to make a choice that may be impossible for him to make.

Chapter 9

The Role of Government

"The future will undoubtedly witness a continued role of government in financing the efforts at prevention, service, and citizenship recognition . . ."

The role of government in America has moved in the past 200 years from one of minimum protection of the rights of citizens to a phase, growing out of wars and depression, of providing services to meet a vast spectrum of their needs. The public financial investment in social programs has grown substantially, and with this growth has come a shift from what was initially a local or State area of responsibility to one in which the Federal Government plays a very large part. Only recently has the Federal level sought to shift some responsibilities back on State and local government, along with funding benefits such as General Revenue Sharing, and to reinvolve the private sector through purchases of service.

Meanwhile, estimates of Federal expenditures for mental retardation by the U.S. Department of Health, Education, and Welfare (DHEW) alone were $123 million in 1963, $735 million in 1972, and nearly two billion dollars in 1976, almost equally divided between services and income maintenance.

Virtually every major Federal department provides some service or activity related to mental retardation. For example, the Department of Agriculture contributes heavily in the area of nutrition for mothers and infants. The Department of Defense provides health services to handicapped children of military personnel. The Department of Housing and Urban Development has programs to facilitate housing of handicapped persons, including those who are mentally retarded. The Department of Transportation is concerned with public transportation access by handicapped persons. The Department of Labor seeks to provide employment and protect mentally retarded workers from peonage. The Department of the Interior provides services for Native Americans, some of them related to the problem of mental retardation. The Department of Commerce provides economic development funds for manpower training that can benefit retarded individuals. And the Department of Justice initiates or participates in suits asserting the constitutional rights of retarded citizens.

The independent Federal agencies which provide mental retardation benefits are numerous. ACTION provides volunteer services through foster grandparents and VISTA volunteers. The Small Business Administration makes loans for sheltered workshops and business opportunities for handicapped individuals. The Veterans Administration provides services for mentally retarded dependents and orphans of servicemen. The Appalachian Regional Commission offers help with respect to mental retardation in its 13 member States. Even NASA is involved through technological benefits for retarded individuals which spin off from its space research.

The President's Committee on Mental Retardation is charged by Executive Order 11776 with "evaluation of the adequacy of the national effort to combat mental retardation" and with "identification of the potential of various Federal programs for achieving Presidential goals in mental retardation."

In all, PCMR has identified* in the Federal effort 22 executive departments and agencies, including 75 organizational units, which provide 91 separate programs in some way related to the Presidential goals of reducing the occurrence of mental retardation and returning mentally retarded residents of institutions to the community.

State and local counterparts materially extend this scope; their expenditures for mental retardation were more than six times the Federal level in 1970.

The government involvement in mental retardation addresses the basic needs of all citizens, but takes into account the handicapping nature of mental retardation. The very elements of human life are the basis of the government programs: prenatal and post-natal medical services, early identification of mental retardation, nutrition, family income maintenance, suitable housing, education and habilitation, recreation, training and placement in employment, transportation, assurance of individual guidance and counseling, and legal protection from harm or neglect. Supporting such direct forms of assistance are programs of research to discover causes and effective preventatives of mental retardation, efforts to translate research findings into practical applications, manpower development and periodic retraining, evaluative efforts to determine what is happening and what is working well, and continuous scrutiny of policies, laws, regulations and funding to assess their impact on the mental retardation problem.

The extent and cost of programs will continually raise the question of how and with whom responsibilities will be shared. The future, therefore, will witness a continuing dialogue among agencies and levels of government and between government and the private sector as to who should be responsible for what. Partnerships will be likely, but will be subject to constant change. Some programs, such as those for income maintenance, will probably continue for long periods with little change. Other areas, such as manpower development, or housing or employment for retarded persons, may be more subject to innovations and intergovernmental shifts of responsibility.

Two emerging themes likely to receive emphasis in the future are equity and accountability. The uneven distribution of services is a chronic cross which government bears and must try to lift from its back. The effort to meet special needs of special populations tends to produce inequity, but the egalitarian spirit of Americans compels attempts to achieve a better balance of services.

Accountability is today's catchword and tomorrow's reality. The demand for more and better distribution of assistance for handicapped and disadvantaged populations in the face of increasing costs can only result in growing emphasis on knowing what government expenditures have accomplished. The accountability which today is primarily an internal government audit, tomorrow will involve reporting to the consumer and his advocates on what benefits he is receiving from government agencies and funds. There will be different consumers to satisfy: retarded persons themselves, the parents and friends of these persons, and the responsible community leaders who must provide them with suitable services and opportunities.

Finally, the future will undoubtedly witness a continued

* More complete information can be found in the book, "Federal Programs for the Retarded," 1972, U.S. Government Printing Office, $2.00.

role of government in financing the efforts at prevention, service, and citizenship recognition in the mental retardation area. The problems are so pervasive and the resource needs so extensive, that the public role in providing or financing efforts will continue to be a major responsibility.

The future role of government in mental retardation involves extremely difficult problems, which, though stated separately, often interact. The more serious are:

Complexity of service structure. In the Federal-State-local structure of government for dealing with mental retardation there is a very attenuated line linking initiative at the public level and consumer need satisfaction. The chain includes not only several levels of government, but the academic and private research and training establishments, and the non-profit and proprietary vendors of service who may be the actual point of contact with the mentally retarded consumer. Thousands of people serving in hundreds of agencies under one Federal, 50 State, and the territorial sets of law, policy, and procedure, and dozens of funding patterns combine to form an almost impenetrable maze of helping channels. In fact, many consumers come to regard the system as really impenetrable, and the service deliverers themselves often are overwhelmed by the complexity of regulations and paper work.

Instability of the helping system. Not only is the system complex, but its arrangements are continually shifting—new agencies, new personnel, new laws and procedures—so that today's catalogue of sources of help is out of date before the end of the lunch hour. When the Supplemental Security Income (SSI) program was introduced on behalf of aged and handicapped persons, expensive training time reserved for the preparation of new staff was consumed daily in simply updating the staff with new information since the previous day.

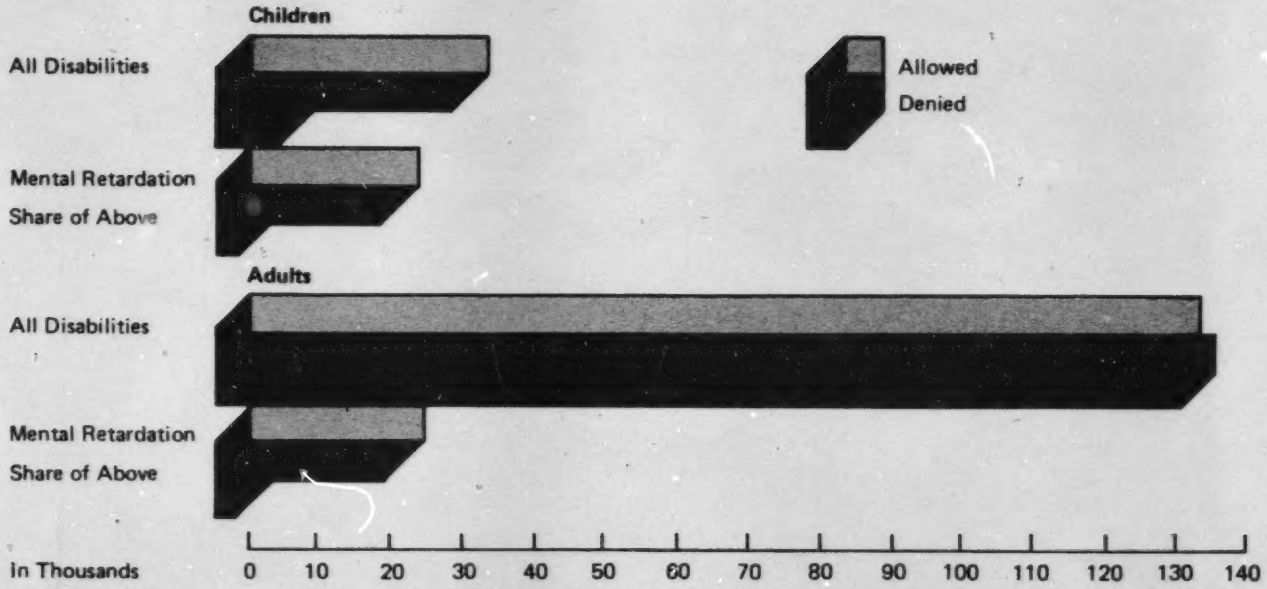
With many of its parts in flux, the helping system requires some dependable and relatively fixed frame of reference. Change will continue to be inevitable, often rapid, and essentially desirable since rigidity can pose even worse problems. Positive momentum must be maintained. In the face of change as the fact of life, the mentally retarded consumer emerges as the only valid reference point, since the satisfaction of his requirements, including the initial prevention of his dilemma, constitutes the goal around which the entire helping effort turns.

Definition of the problem. Mental retardation is not a single problem, but one composed of different parts. There are different levels and complications of mental retardation. There are populations with different vulnerabilities to the condition. There are different life styles that impinge upon the handling of problems of retardation. These are all subdivisions of the problem.

There are other populations which share with mentally retarded persons similar problems. Some of these are represented in the group identified in Federal legislation as "developmentally disabled." Some are represented in a larger context of problems of the handicapped. And there are many problems affecting retarded persons and their families which are common to the general population, but which still must be dealt with in separate program strategies for coping with the problems of mental retardation. These are problems encountered in ordinary experiences of daily living, such as earning income, finding housing, maintaining good family relations, maintaining physical and mental health, and religious and cultural expression.

Inadequate information. Realistic planning requires a solid information base. If government is to offer programs that meet the needs of retarded citizens within the framework of

Supplementary Security Income Claims (Allowed or Denied- Fiscal Year 1974)



Source: Social Security Administration, Longitudinal Studies Branch.

available resources, it must have more accurate knowledge of those needs than it does today. Even such a fundamental as the number of retarded Americans now can only be estimated. Government has vast capabilities for gathering information, e.g. the Census, but the right of privacy must be a balancing consideration in deciding how far those capabilities shall be used.

Problems of inequity. Mental retardation constitutes a category of handicap. Categorical approaches to the solution of problems are inherently unequal. Nevertheless the demand for equity persists, and forces on government the need to try to represent all people equitably. This nagging insistence is indispensable to a society based on egalitarian principles, and must be accounted for in all programs designed to meet the unique needs of a particular handicapped group. Equitable determination of eligibility for the special services needed becomes an expensive process, subject to the additional expenses of legal challenge. Furthermore, application of standards in programs invites complex procedures whose rigidities often yield absurdities and lock out promising innovative programs from the help they might bestow.

Lack of coordination. Probably no problem in government is more exasperating than harnessing co-contributors to a consumer so that their services reinforce one another rather than ignore or compete with one another. The very size and complexity of some government programs forces them into an institutional mold in which all other government agencies become an outside circumstance. It

is patently difficult for such cumbersome organizations to cope with their fellows when their internal demands are so pressing.

This insularity is of course a serious problem to the consumer. He may easily be caught in a Catch-22 situation in which the benefits from one government source cancel out the advantages he hopes to receive from another. He also must face the difficulty of following the skein of yarn through a labyrinth marked "housing" only to have to repeat the process to get through another marked "employment." If this consumer also is handicapped, the problem of access to government benefits is compounded.

There are two types of coordination that are critical: a coincident collaboration of programs all needed at the same time, and a sequential coordination that permits one form of help to follow in time from a necessary preceding one. The process that links most government agencies in either of these forms is characteristically the referral. It merely guides the consumer out one door and points him in the direction of another. The integration of the benefits from entering several doors, assuming the consumer can manage this, is left entirely to him.

This is a problem for all citizens of a complex society, but it becomes a serious one for the mentally handicapped person. In another portion of this report, recommendations have been made that the consumer employ his own trained representative to negotiate the labyrinths of government service organizations. The problem presented here is the coordination problem from the government perspective, and some ways will be suggested for government systems to reinforce one another for the client's increased benefit.

Measuring effectiveness. The human nature of programs for human beings represents a major problem in providing a government role that is truly beneficial and at acceptable cost. Unlike manufactured products, the changes to be produced through interventions are impossible of standardization and the methods themselves cannot be fitted into any tight molds. For this reason, the simple counting of effects and the linking of them with costs has defied most efforts.

The difficulty in finding ways to calculate effects and costs will not in the future excuse governments from developing them. There is a growing public sensitivity to the uses of public money, and even the most straightforward intent for use of such funds may be regarded askance. The emerging strategies of negotiating with consumers plans for achieving specific benefits and measuring progress against these plans are therefore appropriate for the times. The approach has advantages for coordination as well as efficiency. It focuses the effort, the technology, and expenditures on a specific consumer and his needs, and subjects government to being evaluated in terms of consumer outcomes.

The first question to be answered through these devices is that of effectiveness. What really works? The next question is one of efficiency. What works best for the least cost? The development of cost information is a far easier technical problem than the definition of sought-for effects, but both, however difficult, appear capable of future solution.

Because of the leading position of government, and particularly the Federal Government, in future programs of importance to the prevention and amelioration of mental retardation, the following goal is indicated:

Equitable, Coordinated, Efficient, and Effective Use of Public Resources In All Mental Retardation Programs.

This goal can be realized through achievement of the following objectives and recommended courses of action.

Objective I: *Coordinated and comprehensive planning of Federal, State, and local efforts in the area of mental retardation.*

Careful analysis and planning are crucial in providing the mentally retarded consumer with the complex of services, arranged in proper sequence, that can foster his maximum development and satisfy his major needs. No two among the hundreds of thousands of such consumers have

identical requirements. Without planning that takes into account the volume and variety of need and the many sources of help which must be organized to meet such need, the result can be waste, frustration and organizational chaos.

• *The Federal Government should establish a continuing interdepartmental planning system* on mental retardation, responsible for the preparation and promulgation of short-term and long-range plans. These plans should be based on joint assessment of needs and resources and the commitment of the participating departments to fulfill their respective responsibilities under the plans.

The President's Panel established by President Kennedy in 1961 was the first national effort at long-range planning in the area of mental retardation. In further recognition of this planning need, the President's Committee on Mental Retardation, established in 1966 following the interim tenure of a Special Assistant to the President on mental retardation, was given responsibility for coordination of the efforts of all Federal departments.

The President's Committee has continuously sought to involve the Federal departments and their program elements in collaborative planning for the prevention, recognition, and amelioration of mental retardation. It has been successful in the encouragement of improved services to retarded individuals, improved communications among collaborating Federal agencies, the resolution of some problems associated with differing agency roles, and the initiation within HEW of intra-agency planning on a problem-focused basis. The present report represents a further planning effort undertaken by the President's Committee with respect to the long-range roles of all contributors, government and others, to the future reduction of the problems associated with mental retardation.

What is called for now is a regular planning system across department lines, established as a continuing function of government. It should be a planning system based on the active participation of the serving agencies, including their regional organizations. As such, it would represent a logical step in fulfilling the responsibility of the President's Committee.

• *State governments should establish comparable interdepartmental planning systems* at the Governors' level, with similar responsibilities for the preparation and execution of plans for mental retardation programs among appropriate State agencies.

The Developmental Disabilities Councils of the States represent a planning function which in part reflects the intent of this recommendation. However, it is here proposed that with the authority of the Governor, a continuing interdepartmental planning system be introduced which will involve the full program commitment of each participating agency. The manner in which this approach would be undertaken in relation to the planning responsibilities of the Developmental Disabilities Councils would need to be determined by each State.

• The Federal, State, and local Governments should guarantee to all programs in mental retardation, whose effectiveness in relation to planned objectives would require an extended period of operation, *assured fiscal resources for the entire period of the planned effort.*

The risk of wasted opportunity is great when a planned effort is initiated for preventing or coping with mental retardation and the effort falters because of the subsequent reduction or withdrawal of funds. Programs are often forced to defend their budgets year after year when by design their promise cannot reasonably be realized in the early years. Those efforts which seem more remote from the direct provision of services, such as research and training, are particularly vulnerable. In the face of quick shifts in circumstances and priorities, long-range efforts derived from long-range plans should be protected in advance from the influences of immediate political or economic vicissitudes.

Ways and means of safguarding programs have been devised by government for a number of its efforts. One way is the direct taxation approach, such as the Social Security tax on employers and employees, and the mill tax on property used by local government to support special social programs. Another is the early budgeting of funds which are sufficient to carry a program forward into future years. Still another is the fixed funding relationship of special program efforts to the basic effort, such as a fixed percentage allocation of total program funds for research or program evaluation. These and other methods which may be designed, should be relied on to protct long term plans.

In those situations where a period of time, such as five years, may be required to establish the efficacy of a new program or method, the protection need only last for that period, and the program or method should then be required to hold its own competitively in the funding arena on its demonstrated merits. The precondition of guaranteed funding must be effective planning and stringent review of proposals to insure their soundness, relevance to goals and objectives, and quality of effort.

• The Federal Government should create a *national information system* on mental retardation through which its departments and the States may get prompt and reliable intelligence on which to base their planning efforts.

The field of mental retardation does not have an effective means for acquiring and using information on the nature and distribution of the mental retardation problem and the strategies for preventing or coping with it. There have been limited types of national reporting which have provided useful, partial information, frequently published much later than the events reported. The information-gathering responsibilities have been distributed among a number of Federal agencies, and efforts at compilation have faltered with changes in agency responsibilities. Many questions of policy have not been covered by the information available. Special studies undertaken to fill in gaps have themselves been limited in scope. It may never be possible to have available the answers to all the questions which are raised by mental retardation, but there are many very practical ones for which answers could be available. In the absence of information, planning and administrative judgment must continue to rely on error-prone estimates and unsubstantiated assumptions.

In an age of information explosion, this situation has been addressed in limited degree by experts in the use of new, computerized forms of data-gathering and analysis. Various strategies for the acquisition of scientific, management and clinical history information have been developed, and some of these have been introduced to the field on a pilot basis. They do not add up at this time to a national information base, nor even provide comparable State bases.

Present methods suffer chiefly from two pervasive flaws: (a) absence of efficient, uniform, and time-saving methods of reporting pertinent data from all appropriate sources, and (b) confounding incompatible objects in the collection of data, e.g., the objective of statistical compilation and analysis and that of case registry and tracking. Basic technology for an adequate information development and retrieval system is available; government needs to exploit it.

• Federal, State, and local planning should enlist *consumer panels*, representing mentally retarded individuals themselves as well as their families and other representatives. These panels should be invited to participate in planning activities so as to assure that planning correctly reflects the interests of those persons for whom it is undertaken.

The consumer movement on behalf of mentally retarded persons until recently has been composed almost completely of families, other interested citizens, and professionals, who have undertaken to represent the interests of retarded individuals in the absence of any way in which these individuals could represent themselves. The National Association for Retarded Citizens, with 25 years of experience and 250,000 members, has been a substantial voice on behalf of consumers. Other related groups, smaller but no less active, have been similarly involved. Scientific advocacy has come through such organizations as the American Association on Mental Deficiency with its 40,000 members, and the Council for Exceptional Children.

A new development is self-representation by mentally retarded individuals themselves. Some of these handicapped persons have exhibited remarkable capacity in the face of their handicaps to articulate their needs and expectations. In Oregon, a Statewide organization of retarded citizens has been formed. It is self-directed, and functions through 17 local chapters. It has conducted two annual conventions, the last of which was attended by over 600 retarded individuals. The ability of retarded individuals to form their own organizations and to discuss and present their own viewpoints signals a time when they are ready to be actively involved in planning efforts on their behalf.

Objective II: *Assure, through Federal, State, and local organization and leadership, that program activities involving joint participation of two or more agencies serving mentally retarded persons will be planned and conducted in a coordinated and collaborative way.*

While interdepartmental and interagency planning hopefully lay the groundwork for mutually reinforcing efforts of agencies in dealing with mental retardation, it is the actual performance of these agencies which assures coordination of effort. Since well-laid plans often go awry, it is a responsibility of government to take preventative and remedial measures to insure against such breakdown. Some of this must be done within the government structure. Some can be done at the level of the mentally retarded consumer himself. Independent or competitive functioning of related programs should be discouraged.

• There should be established in each major department which provides services in relation to mental retardation, the position of an *advocate, responsible to advise the department administrator* of problems observed in the coordination of agency program efforts, to initiate efforts to resolve conflicts and effect solutions, and to call attention to program resources and authorities which may not be fully utilized in the best interests of those being served.

This position partakes of the qualities of an expediter, troubleshooter, and gadfly. It must be a staff position with access to the program manager, or it will suffer from the experience of many agencies which have assigned program coordinators without authority to influence events.

• Federal departments should, through bilateral or multilateral agreements, develop routine means to *identify and resolve conflicts in policy*, reflected in proposed or enacted law, proposed regulations, and instructional materials, which may result in one program's operations interfering with the realization of benefits from another.

Conflicts between programs occur despite present efforts to avoid them. They sometime lead to total canceling out of benefits of either program. A housing rent supplement program may cancel out an SSI benefit and conversely the SSI grant cancel out the rent entitlement. The difficulties in resolving these conflicts after the fact are great. Since departments have within themselves some means for policy coordination to avoid such contradictions, the recommendation is that this practice be raised to the interdepartmental level.

• Each major department providing services should provide a *casefinding and access program* to inform all known mentally retarded persons about services to which they are entitled, and guide them to sources of help in a fashion that assures they are actually offered such help.

Recent experience in such social programs as Supplementary Security Income and food stamps indicates that not all potential recipients of the benefits of these programs choose to use them. This is the prerogative of a citizen who makes a choice on the basis of identified options. Many potential beneficiaries of these and other programs, however, do not even know that such programs exist, or that the programs may apply to them. To the extent that this is true of mentally retarded persons and their representatives, it should be a responsibility of any serving agency to notify them.

Once notified, they face problems of convenient access to sources of help. Impediments may be financial—the absence of carfare. They may be geographical—services at too great a distance to be of immediate value. They may be social or cultural—help being offered in a strange environment in which the potential applicant may not feel secure. These are solvable problems, given an intent to solve them and agency resources for doing so. The access is not completed until a helping hand is stretched out to assist the individual in need.

Needed benefits often are so scattered as to discourage the potential user from trying to get to them. The provision of outreach and access services by each agency collaborating in joint services should help overcome this serious barrier to effective service utilization.

A growing network of agencies and functions are attempting this type of casefinding and access assistance, particularly in the social services. Variously called outreach programs, information and referral services, and information centers, these programs attempt, on behalf of applicants for public and private social services, what is here recommended for all mentally retarded consumers. Efforts of this sort can be supplemented by such innovations in the voluntary sector as the consumer advocacy movement or the service brokerage concept, through which retarded individuals are assisted in obtaining needed services.

Objective III: ***Federal and State accountability for the provision of effective services in an efficient manner and with due regard for the consumer's rights of redress.***

Too often, programs become accepted fixtures and continue year after year with no one examining whether they are fulfilling their mission. Indeed, the mission may not be clearly defined, and standards not established for measuring progress of those served. There are current signs of dissatisfaction with this state of affairs, and expectations from serving agencies, consumers and the general public for manifest evidence of accomplishment.

While it is difficult to introduce accountability systems in human service areas, it is not impossible and is being attempted with increasing energy. The mental retardation mission needs to share in this effort. The accountability needs to concern itself both with the benefits to individuals and with program impacts on the general community problem, in humanitarian and economic terms.

- Federal, State, and local agencies should require of all case services provided or funded with their assistance, that a *mutual agreement for the service* and the purpose which it is to meet be negotiated with each person served, and that the degree of fulfillment of such agreements form one basis of determining the effectiveness of service. The confidentiality of such records must be safeguarded.

There is a growing use in service agencies of the service "contract," a definite specification of what the applicant wants that the serving agency is prepared to supply. This form of understanding, when placed in the record, provides the necessary reference point against which evaluative judgments—by client, agency, or independent judge—can be made.

- Federal and State agencies responsible for providing or funding services should establish systems for *periodic monitoring* of program achievements and case benefits, and for evaluating them against both program and fiscal standards.

Case evaluations, based on the achievement of objectives in relation to needs of individuals served, can be based on predetermined goals of service and the costs of goal achievement. The compilation of such individual evaluations provides one important dimension of program evaluation. Another dimension is the extent to which programs affect larger community problems, as in the prevention of future mental retardation.

To keep such findings accurate requires periodic monitoring of the record-keeping and evaluation processes themselves. Each program should set aside funds for monitoring and evaluation. Findings should be used for improving the efficiency and effectiveness of programs, and for informing the public of the value of programs.

• A *prompt administrative appeals procedure* should be offered by all Federal, State, and local agencies responsible for providing or funding services. If a mentally retarded person or his representative feels that he is not receiving services in accordance with his express need, he should be able to count on an impartial review and on an appropriate and prompt remedy.

If an agency is to be accountable for its agreement to provide a service or benefit, it must offer the retarded consumer a means to challenge the agency for any failure to meet his expectations. Since redress in the courts is costly and lengthy, large programs usually seek settlements through an administrative review process. These review systems can be set up on an impartial basis, separated from the program against which the complaints are lodged. If properly organized, they provide a relatively informal and supportive atmosphere for the disadvantaged client to bring his grievance up for consideration and receive a prompt remedy. In very large programs, however, this administrative appeal procedure also may become seriously delayed. Because time is usually the essence in such matters, the appeals procedure should be so constructed as to forestall the additional penalty to the consumer of protracted delay.

"Everybody needs someone because if they don't have anybody . . . they're lost."

To reach his place, we walked up a flight of wooden steps on the outside of a large old frame house. Inside were more steps leading to his apartment door. We could tell he was at home because the hasp and padlock weren't secured. He opened the door when he heard us coming, and we walked in. The shag carpeted living room was only large enough to hold a divan, a television set, a small desk, his stereo record player, Freddie the parakeet's cage and the precious telephone. The next room, containing a twin bed and dresser, wasn't any larger except for the tiny nook housing his stove, refrigerator, and cabinets. His own personality was reflected throughout the unit. He showed us a framed pencil sketch of his face, drawn by a friend, and a large collage of photoprints of himself from a TV documentary which had been assembled and framed by another friend. Added to this, we saw assorted landscape prints, his stack of bargain LP records and four bowling trophies. This was Sam Diamond's garret apartment; cozy, clean, and neat.

"The apartment already had a couch and bed and things," Sam told us, "but most of the stuff I bought from scratch . . . like the tv, and the record player. The landlord likes me. He says he's never had anybody keep this place as clean as I do. So you see, I'm tryin' hard to make it on my own.

"I've come a long ways since leavin' the institution six years ago. I made it this far because all the house parents and counselors liked me . . . and they're always pulling for me. I sure don't want to mess up now. (Silence) . . . See all those records? I bought most of 'em for 88 cents on sale. One of my favorite singers is Tex Ritter."

Sam plays four of his favorites for us. Judging from the way he hummed along, his greatest satisfaction came from listening to deep-voiced Tex sing. . .

"I gotta walk that lonesome valley
I gotta walk it by myself
Nobody else can walk it for me
I gotta walk it by myself."

"When I first got out of the institution I was scared. But the counselors and the people in the group homes helped me. When I got upset, they cooled me down. If they hadn't liked me . . . and helped me . . . I never would have made it livin' alone in this apartment.

"Let me tell you about the birthday party they had for me two weeks ago. One of 'em picked me up to go get a drink . . . and we drove to a friend's place where everybody comes out yellin' 'surprise!' . . . and we had all those presents and we drank beer. What a way to have a 36th birthday!

"Some people think I've jumped around on jobs too much. Well, I have had a lot of 'em. They let me go at Hardings Cafeteria because I popped a guy, but he kept bothering me until I couldn't take it no more. I lost another job because of a seizure . . . and I was doing good on the construction job, but they didn't pay me because they didn't get paid. Besides, I always get another one. Right now I work nights cleaning a movie theatre.

"Some folks say I talk too loud. In the institution that was the only way a guy got anything. There's people who think I'm fresh with the ladies. I don't mean no harm. I'm just trying to be a friend. The counselors keep saying I can be calm. They say I'm learning.

"A bunch of the counselors got together with me the other day and they talked about my individual program plan . . . and you know, I'm doing pretty good. They have this list of things they check me on. They told me how well I learned to clean my apartment . . . buy my own clothes . . . and keep myself clean. I'm taking my own medicine now. Gotta watch that like a hawk. I even do my own grocery shopping and laundry. A counselor still comes over and checks on me every now and then. I'm learning to handle my own money without blowing it. I tried to make out a money order

to pay the phone bill . . . and I did it. Boy! Gotta keep up on payin' for that telephone!

"I have all my friends that I call on the phone. I call 'em one after another to see how they're doing. Sometimes I play my favorite records for them on the phone. The counselors say I use the phone too much, but I like talking to people. Anyway, I don't hold people on the line as much as I used to.

"What do I do when I feel lonely? I let my parakeet out of the cage and he sits on my hand, like this. Lookit. Freddie's a tough little bugger. He really knows how to peck at 'ya. Sometimes he scolds me.

"What would I like to do someday? I'd like to be a truck driver . . . travel all over the country . . . go places and see things, but I'm not ready for that.

"There is something else I'd really like to do. Lots of little kids are coming out of the institution now. All those years I lived at the institution they had me working with the younger ones. I was good at helping 'em. Now I'd like to help 'em make it in town. I know what it's like. Sometimes people can be awful mean . . . like the time those guys picked me up and beat me up and robbed me and dumped me out at Calumet City. I didn't cause them any harm. Well, those little kids that are coming out . . . they're gonna need help. I'd try to teach 'em everything I'm learning. Everybody needs someone because if they don't have anybody . . . they're lost."

Chapter 10

The Century of Decision Program: Costs and Results

"For 95 percent of retarded people, the investment of public and private money in developmental programs provides the prospect of a return . . ."

The preceding chapters have set forth a comprehensive body of proposals for substantially reducing the occurrence of mental retardation and ameliorating its impact on individual lives, families, and communities.

The time span of the proposals is the next 25 years. The objectives identified under the seven major goals should be substantially achieved by the end of this century. They are put forth with the conviction that knowledge and resources will be available, if wisely and effectively applied, to accomplish the task.

The central problem for government and private agencies dealing with mental retardation is to plan and carry out programs that are within the limits of the economy yet make progress toward humanitarian objectives. While organizations have always had to concern themselves with costs, it has now become indispensable in planning to calculate the investment required to initiate or modify programs. In the restricted economy of today any new call for expenditures is subject to rigorous question and analysis.

The proposals of this report call for a wide range of actions, many of them involving investment of resources—money, manpower, materiel. They are made with the full knowledge that the resources required may not be immediately available. This report, however, looks to achievements by the end of the century, and sets forth recommendations which can be accomplished in that time. The future of America is a bright one, and temporary periods of restricted resources will be followed by periods of improved circumstance. It is in this context that the recommendations are made. They represent a confidence that within a reasonable time the resources can be at hand for realizing the goals and objectives presented.

There is a tendency in these days of improved econometrics to seek to justify program efforts on the basis of their positive economic results. There is stress on measurements of cost in relation to effectiveness and as a measure of efficiency. These are important considerations as Americans become more alert to the balance between their investments in public programs and the outcomes of such programs. Under the general label of program evaluation, most agencies now seek to learn how well they are doing and what impact they may be having on the future. When administrators of a program can project a future benefit that is humane or economical, they can argue for the resources to support it.

Without any intention of disregarding the central role of costs and resources, we must stress a prior point, the human welfare of those served by programs. This is of special consideration when speaking of severely handicapped individuals —five percent of the retarded

population—for whom society accepts a measure of responsibility, perhaps lifetime responsibility, in those aspects of human life which they are not competent to manage. While their developmental prospects do not permit anticipation of substantial self-care, their human needs and rights are no less important than those of any other. There will always, therefore, be program costs for such persons without the offsets of production and earnings. Evaluation must look to the human benefits such persons receive before looking at the costs.

By far the major portion of America's retarded people are only mildly or moderately retarded, and the community can expect them, with appropriate support and encouragement, to develop cost-saving abilities for self-care, self-maintenance, and employment. For such individuals, development means both the self-respect and choice of a free citizen as well as the ability to become a producer rather than merely a user of community resources.

It is encouraging that for these 95 percent of retarded people the investment of public and private money in developmental programs provides the prospect of a return on the investment. One can look forward to meeting a human goal and at the same realizing an economic one.

The proposals in this report for halving the occurrence of mental retardation from biomedical causes clearly have high benefit-cost prospects. For every dollar invested in preventive public health and health care measures, public education, and continuation of research in critical areas, 100 dollars can be saved. The present number of severely and profoundly retarded persons is estimated at 300,000. They require total care at an annual average cost approaching $18,000 each. If by the year 2000 prevention could cut the number of such persons in half, the annual savings would be $2.7 billion! The savings in non-economic costs of emotional distress, family disruption and quality of life would be incalculable.

Prevention of milder forms of retardation is more complex and more difficult to evaluate. Since it is closely related to the environment of poverty and deprivation, the problem has two major aspects:

- the prevention of retardation in children born into environments of social and psychological risk, and
- the alleviation of the social and economic conditions creating the environment of poverty with all of its attendant social ills.

In the former case, methods of protecting individual children by assisting the family in providing developmental stimulation are now showing success; continued investment in pilot and demonstration programs, coupled with improved management in school settings, improved human relations, and better qualified personnel can save a great many children from the functional retardation to which they are now susceptible. Because the methods of intervention require high personnel-to-client ratios, cost per case is likely to run high, especially in some deeply deteriorated or isolated environments. But the benefit-to-cost ratio appears to be favorable in terms of developing fully independent and productive members of society.

The second aspect of sociocultural prevention is far more massive and constitutes a core problem of contemporary society. Reducing poverty itself, in both absolute and relative terms, and overcoming the ethnic, racial, and other demographic lines of tension which contribute to the developmental risk of children of poverty—these objectives require the most thoughtful, persistent and determined efforts.

The present economic and human costs of poverty and cultural disadvantage are staggering in terms of their by-products of disease, mortality, malnutrition, crime and delinquency, civil disturbance, unemployment, alcoholism and drug addiction, and social disintegration. The whole of society is paying these high costs.

It may appear somewhat visionary and presumptuous to declare that the way to prevent sociocultural mental retardation is

to get rid of poverty; but the evidence is clear that poverty with its by-products is a root cause of the impaired and maladaptive development of three to five million American citizens. Retardation is only one of the products of the environment of poverty; consequently, its reduction would be only one of the benefits to be taken into account in evaluating the costs of reducing poverty.

Because of the intricate interrelationships between biomedical and social-cultural causes of retardation, the two lines of effort toward reduction of incidence and the cost-benefit analyses of both types of prevention programs must converge at many points.

No conceivable efforts to reduce the occurrence of mental retardation will *fully* eliminate it in the next quarter-century; all those who are now or who become retarded will continue to require varying degrees of care and support. Therefore, the issue of ameliorating the effects of retardation will remain a paramount one.

The ameliorative objectives cited in the report are directed towards reducing the dependency, increasing the self-sufficiency and normalizing the social functioning of retarded persons. These objectives lend themselves to program evaluation which takes into account both costs and results. Such evaluation is essential in order to determine the best use of social and economic resources in serving mentally retarded citizens in relation to all other problems making demands on the same resources.

During the past 25 years, considerable progress has been made in providing opportunities for retarded people to make the best use of their abilities and to live more satisfying, normal and productive lives. During that time, efforts went through three stages:

- methods of control, based principally on the view of the retarded person as a genetic and social threat to the community
- methods of care, based on the view of the retarded individual as a perpetually childlike incompetent who requires primarily humane protection
- methods of development, based on the view of the retarded person as an individual with rights of citizenship and capabilities of development and usefulness in the social and economic community.

This last view has been bolstered in recent years by numerous court cases upholding citizenship rights. It is essential to understand these shifts in perspective, because they influence greatly the context in which "benefits" in program evaluation are now considered.

Although knowledge is still far from complete, and even existing data have not been effectively accumulated and appraised, a number of assumptions with respect to elements affecting program evaluation may be made.

- The focus of benefit in the provision of services to retarded individuals is in the development of the human qualities of the person. If economic savings also result, they represent a bonus, but not the primary objective.
- All retarded persons, of any degree of severity (with the possible exception of a very few who lack all capacity to respond to stimulation), are capable of learning in ways which increase self-direction and reduce dependency; all learning has both non-economic and economic values.
- The great preponderance of retarded children are capable of developing sufficient competency to be partially or wholly economically self-supporting adults.
- Provision of supporting services enables those who remain less than fully independent to use their developed skills and capabilities in socially productive and adaptive ways; and without such support their capabilities remain unused and represent economic and personal waste.
- Individual differences among retarded persons and the environments in which they live are highly varied. Programmatic concepts must, therefore, be highly flexible and definition of benefits adapted to individual variations.

The costs of mental retardation programs are now, and will continue to be distributed between the public and private sectors and among the various levels and components of each. Public costs are divided approximately 10 percent Federal and

90 percent State and local. The private costs fall probably about 70 percent upon families, with 30 percent divided among voluntary fund-raising operations, service organizations, and private foundations. The percent division between public and private sectors is difficult to estimate with any precision because of the lack of hard data, especially on family contributions.

The recommendations of the President's Committee envisage the continuation of a wide distribution of costs among the above sources. Some increase in the proportion coming from the public sector is needed to reduce economic pressures on families, especially those with retarded adult relatives. For development and prevention activity to reach optimum levels sometime in the next quarter-century, an increase in total investment, from public sources and the private sector other than the family, will be necessary as the economy permits. Then as a reduction in new cases takes effect, funding needs may conceivably decline.

Meanwhile, the role of the Federal Government is seen as crucial in

- Stimulating and sustaining active effort by the States in their provision of essential services,
- Maintenance of quality requirements in such services,
- Support of research including the field testing and application of new knowledge,
- Support of manpower development in critical fields and with equity to all regions of the country, and
- Provisions for equitable income maintenance.

Factors offsetting the increased investment in this period will be:

- Increased productivity of retarded people as their abilities are developed and brought into use,
- Tax contributions from earnings, and
- Savings in costs of intensive care as the retarded person learns to meet some of his own needs.

The President's Committee strongly encourages the development of rigorous program evaluation in justifying and accounting for the use of both public and privately contributed funds. The Committee warns, however, that procedures of program evaluation in this field are enormously complex and difficult.

The difficulties of collecting data in sufficient detail on well-defined and relevant elements, and converting such data to measurable terms, make valid program analysis an extremely difficult task. For the field of mental retardation, with its great complexity, most decisions will retain highly subjective elements. This does not mean that decisions of a positive nature should not be made, nor that evaluation should not be as well done as possible. It means that we must develop a much more complete and better organized data base than we now have. It means that we have to improve the conceptual and operational tools used in analysis. It means that we have to recognize and make explicit the underlying assumptions and values on which proposed courses of action and program operations rest.

The President's Committee recommends that continuing attention be given to these problems without delaying action on the overriding human objectives of this report. These objectives, and the recommendations for accomplishing them, are recapitulated in the section that follows.

The Committee believes that if we address these objectives with the realism and idealism that combine in the American character, they can be achieved in this century of decision.

Chapter 11

Goals, Objectives, and Recommendations

In the preceding chapters, the President's Committee on Mental Retardation has stated goals, objectives, and recommendations in the context of the situation they are designed to meet. For each, a rationale is presented.

Readers, however busy, are urged to look at the recommendations first in that complete form. The listing that follows then can serve as a handy reference.

Chapter 3—Full Citizenship and Legal Rights

Goal:

The attainment of citizenship status, in law and in fact, for all mentally retarded individuals in the United States, exercised to the fullest degree possible under the conditions of disability.

Objective I: *The assurance of maximum freedom to exercise legal and constitutional rights and responsibilities.*

Recommendations:

A duly selected body, working in concert with public and private agencies, should *develop at an early date a legislative guide and information-sharing system,* to be used by the States to develop statutes to protect the constitutional rights and facilitate full citizenship of mentally retarded and other handicapped persons.

All States that have not already done so should institute a careful review and revision of their statutes and legal practices relating to mentally retarded and other handicapped persons, to ensure conformity with constitutional guarantees of equal rights, due process and equal protection of the laws.

A nation-wide system of "public" legal advocacy services specializing in the protection of rights should be available to mentally retarded and otherwise handicapped persons. Branches of this system shoul l be established in all States.

Offices of special appeal, with final recourse to the courts, should be available in each State to protect the rights of the retarded and other handicapped individuals, as well as those of others. The offices should be established as commissions or public corporations separated from the regular governmental systems, with authority to act independently on behalf of handicapped citizens.

Statutes and court procedures bearing on competency should be clarified and revised a) to recognize gradations of competence, b) to recognize that areas of competency may be quite varied and therefore should be separable in law, c) to assure full and explicit due process safeguards on any and all areas of competency, and that the scope of any judgment of incompetence is made fully explicit, and d) to ensure that restrictions of competency be limited to a specific period of time or subject to periodic review.

The LEAA program of the Department of Justice should concern itself with a variety of matters affecting mentally retarded persons in both the civil and criminal justice systems. These would include the clarification of procedural matters; pre-service and in-service training of lawyers and law enforcement, court, juvenile justice, and criminal justice personnel in the nature of retardation, the legal and constitutional rights of hand-

icapped persons, and procedures relating to retarded individuals; and the provision of funds for research and study of these matters.

All professional persons who work with mentally retarded individuals should be trained to recognize issues of human right, including but going beyond legal issues.

Educators, social workers, and other counselors should be trained to impart to mentally retarded persons an understanding of their rights and concomitant responsibilities in a more open society.

Establishment of programs 1) to prevent delinquency in retarded persons at risk, 2) *to divert the handling* of retarded offenders from the regular criminal courts to other procedures, and 3) *to provide corrective rehabilitation* of retarded juvenile and adult offenders.

Every effort should be made to consider and *resolve issues in regard to maintenance of and access to records* of handicapped and other persons. The issues revolve around the rights of privacy, personal access, confidentiality of communications, "need to know," and appear to involve issues of conflict of rights.

Objective II: *The assurance of maximum independence of retarded citizens.*

Recommendations:

The development of a compendium handbook, subject to annual revision, codifying statutory provisions of the States and Federal Government concerning

- Legal status, competency adjudication, and guardianship (both of person and property) for mentally retarded persons
- Protective, developmental, and supportive services for mentally retarded persons.

Development by progressive steps of a system which will guarantee *fully adequate economic security and independence* to all people, including mentally retarded individuals. Such a system should begin with current Federal and State programs and develop over time the following provisions:

- A guaranteed minimum income adequate to meet the normal costs of daily living.
- A credit or voucher system, vested in the individual retarded consumer in need, whereby retarded individuals could acquire necessary special services from a choice of accredited providers. (See Humane Services, Chapter 6, Objective I.) Nothing in these recommendations exempts service—providing agencies from the application of eligibility standards or from accountability in expenditures as provided by law.

In any modifications of economic security statutes, HEW and the States should *provide by law and regulation, for the recognized privilege of any certified personal representatives,* selected by, or under contract to, a mentally retarded person or his legal guardian, to serve as his agent and to negotiate for services in his behalf.

The Federal Government should provide *financial assistance to the States to cover costs of transition* of individuals from institutional to community services, and costs of transforming or replacing central institutions for more functional purposes consistent with the needs of retarded citizens.

A public corporation or commission should be established in each State to provide guardianship services, including the certification of persons qualified to serve as personal representative agents. (See Chapter 6, Humane Services, Objective III.)

Legislation should be developed by the Congress and the States to *authorize and fund adequate systems of humane services* to develop, support, and protect the rights of retarded persons as citizens. (The content and structure of such services are set forth in Chapter 1 and in Chapter 6, Humane Services.)

Objective III: *The assurance of maximum access to a free and open community.*

Recommendations:

Institutional commitment, non-voluntary or voluntary, should be prohibited by law except through due process procedures establishing that it is required to prevent the person from doing harm to himself or

others, that it is the least restrictive solution available, that the period of commitment is specifically limited and subject to court review, and that the subject is represented by counsel at commitment hearings.

Public laws should be established and enforced requiring the use of positively assisting *devices to enhance the freedom of movement and safety* of the *mentally and physically handicapped* in all public buildings, transportation systems, public ways, and publicly financed housing.

State laws and local ordinances should protect the right of handicapped persons to *appropriate residential arrangements*, free of discriminatory zoning regulations, inappropriate licensing standards and codes.

Chapter 4 Prevention: The Right To Be Well Born

Goal:

Reduction of the incidence of mental retardation from biomedical causes by at least 50 percent by the year 2000.

Objective I: *Full commitment of the people of the United States to the prevention of mental retardation from causes operative in reproduction and prenatal development.*

Recommendations:

A national education effort supporting planned pregnancies, which emphasizes optimal conception and maternal health, will be the most effective means to reduce incidence of mental retardation. This effort will ensure the early use of known ways of avoiding the occurrence of mental retardation.

Genetic diagnostic and counseling services are needed by high-risk persons. Outreach genetic services must be extended from university and medical settings to more people in need, especially those in rural settings and in vulnerable population groups.

Couples should be encouraged to take due account of what is known about the *timing of pregnancies* in terms of maternal and paternal age, and to have their children during the optimal reproductive age.

Couples should avail themselves of all knowledge that will improve the probability of bearing normal children. The *discussion with one's physician of any factor in family history bearing on mental or physical problems* may aid in identifying couples at risk for mental retardation. This may be followed where needed by genetic counseling or application of preventive techniques which can reduce disabilities from inherited factors and allow the birth of normal children.

Objective II: *A health delivery system is needed which assures equal access to quality care at reasonable cost.*

Recommendations:

Comprehensive maternal and child health care services must be available and accessible to all women and their children, including those families with low income and those residing in rural areas.

Exposure of pregnant women to radiant energy sources, infectious agents, dangerous drugs, and other known and suspected hazards should be minimized until research has clarified the extent of danger these influences pose for the developing fetus.

Malnutrition, which is a contributing factor to prematurity, low birth weight, and neurological abnormalities, should be decreased by all means available, including public education on known nutritional hazards, accurate consumer information on nutritional values of processed foods, and by selective supplementary diet for high-risk pregnant and lactating women and their children.

Routine periodic developmental assessment of all preschool children from birth should be-

come a normal and accepted part of child-rearing practices in order to detect and treat incipient developmental problems at an early stage.

Programs for prevention and treatment of child abuse are necessary to reduce risk of brain damage. Physical abuse of children can cause neurological damage including mental retardation. It should be noted that some children with mental retardation are at an increased risk of being abused.

Persons with mental retardation must be served in all health care systems, both medical and dental, available to the general public.

To reach all persons in need, a *more equitable distribution of health manpower and resources* must be developed. Medical, communications, and transportation technologies must be more broadly exploited.

An interim system of cooperative funding can provide the needed preventive and ameliorative health care during the next decade. Intensive study of its operation can lead to development of subsequent funding systems during the balance of the century.

More rigorous identification and eradication of toxic substances in the environment, such as lead paint, airborne lead, waterborne mercury compounds, and specific organic toxic compounds, should be pursued.

Objective III: *Continued advancement of knowledge through research.*

Recommendations:

Advancement of basic information in reproductive biology is needed in order to understand and to ensure normal fertilization and gestation, and to reduce incidence of genetic error.

A broader understanding of fetal development will offer options for diagnosis and treatment in the prenatal period.

Research is needed to improve contraceptive alternatives to reduce unwanted pregnancy and allow optimal planning of reproduction.

New approaches and techniques are needed for *improved research analysis* of such complex medical/social problems as nutrition, child abuse, drug abuse, and environmental hazards, and their effect on incidence of mental retardation.

Research methods are needed to explore child growth and development following maternal disease during gestation, obstetrical complications, prematurity, and prolonged respiratory support. Continued fetal research is needed to assess the impact of environmental agents which may have toxic effects, or produce congenital deformity or genetic mutation.

The effects of maternal drug use and drug abuse on the fetus require research.

Emphasis should be given to those *goal-oriented research programs* that address identified problems and produce the most cost-effective prevention of mental retardation, but not at the expense of broad basic research.

A major effort is needed to bring together separate research findings systematically for more effective compilation, technical implementation and application to prevention.

An effective information center should be established at the national level to identify and monitor current research related to prevention of mental retardation in order to improve the flow of information and its application in service delivery.

A coalition to include private, public, and consumer groups is needed to gain broad support for biomedical, behavioral, and environmental research designed to prevent or ameliorate mental retardation.

Public education must be developed to create understanding of the benefits to be derived from basic biomedical, behaviorial, and environmental research.

Research and demonstration programs are needed to further develop effective strategies for facilitating advancement of young developmentally delayed

and mentally retarded children. Such programs must be field-tested on a broad scale before being implemented on a massive basis.

Objective IV: *A total campaign of public education on the known means of preventing mental retardation must be developed.*

Recommendations:

School curricula at all appropriate levels should include information on the following subjects related to parenthood:

Human reproduction;
Growth and development of children;
Importance of the parent-child relationship in the social, emotional, and cognitive development of the child;
Hazards of some modern life-styles to the birth of normal children.

Education for health-related careers should include training in the following areas:

Consumer participation and social problems;
Inter-disciplinary team collaboration in patient care;
Administration of multi-disciplinary service programs;
Preventive and public health aspects of all health specialities in relation to problems of mental retardation and developmental disability.

Various chemicals, some medications, and excessive amounts of alcohol and nicotine during pregnancy can increase the risk of having a mentally retarded child. *Women should be impressed with the importance of seeking their physician's advice* before using any such products when planning pregnancy.

The public should be informed that chemical and other environmental pollutants exert unknown but potentially hazardous effects on the developing fetus. Such awareness should provide added impetus to the necessary research and enforced controls of environmental hazards.

Obtaining medical care early during pregnancy ensures the best opportunity to monitor both the mother's and the baby's health. The importance of such early care should be brought before the widest possible public.

Chapter 5 Prevention: The Right to a Good Start in Life

Goal:

To reduce the incidence and prevalence of mental retardation associated with social disadvantage to the lowest level possible by the end of this century.

Objective I: *Elimination of prejudicial attitudes and discriminatory practices based on race, ethnic membership ("racism") or social class as a root source of impaired or retarded human development.*

Recommendations:

The President of the United States, the Congress, and the Courts must exercise continued leadership in the *elimination of attitudes and practices that create disadvantage* to minority persons in achieving their potential human development.

Affirmative action in compliance with statutory requirements must be vigorously implemented to *assure that minority and disadvantaged individuals will be appointed* to boards, commissions, and administrative positions with decision-making responsibility on matters affecting the developmental opportunity of all persons in need.

The selection of personnel in all departments to administer Federal and State programs designed to meet the needs of poor and minority group persons must include consideration of appropriate experience, training, and sensitivity to the special problems, attitudes and value systems reflecting ethnic and economic differences.

Community Action Programs should be continued and funded on a national level with emphasis on greater involvement of poor and minority persons in decision-making and on the creation of a climate of self-esteem and personal worth conducive to personality growth and mental development.

Objective II: *Improvement of home and community environment and living experience through a persistent attack on conditions which impede or distort full development of human potential among poor and minority groups.*

Recommendations:

The national Home Start program to assist low-income parents in the early developmental training of their children in their own homes should be developed systematically as knowledge and experience expand. This effort should use the best means available to stimulate the cognitive development of children through parent-child and other social interactions, with due respect for cultural differences.

Continued and sustained research at basic and applied levels must be supported by appropriate Federal agencies to develop knowledge and implement the best means of early assistance to families and children at risk from psychological and social hazards.

The total home and community environment must be improved for minority, poor, and otherwise deprived people in areas such as housing, health services, recreation, employment, and nutrition.

The current welfare system should be revised to provide for the training and utilization of *welfare service workers indigenous to the neighborhoods* to which they are assigned. Based on intimate knowledge of their constituencies, such workers would provide welfare recipients a basic consumer education relating to purchase and preparation of food for adequate nutrition, making and buying clothing, purchase of needed services, and other aspects of home and family management.

Access to child development centers for poor and minority group children should be on an equal basis with all families in need of such service. This would be supplemental to home-centered training programs recommended above. Such centers should be strategically designed and located to serve both urban and rural communities.

Monetary aid must be provided to low-income parents for education and employment training as a means of improving the economic and psychological life of the family.

More direct health services to needy families should be provided on a progressively improving basis. Such services should stress preventive and ameliorative measures of all kinds relating to hazards to child development and mental functioning.

Objective III: *Equal educational opportunity for all persons, encouraging cultural differences without penalizing and damaging development.*

Recommendations:

Methods and procedures must be improved for determining the educational needs of individual children exhibiting problems in school. Labeling and assigning children to classes for the mentally retarded by cursory procedures employing inappropriate tests is discriminatory and unjustified, especially when applied to children from cultures other than those on which tests have been standardized.

In support of the previous recommendation, *broad programs of educational research and development* should be Federally funded over the next 25 years to discover and develop the best approaches to equitable individualized education for all children, including the development of improved, culturally sensitive assessment methods.

Curricula for certification of teachers, administrators, and other educational personnel should include courses focusing on both the positive and negative impact of racial, ethnic, and economic factors on human development.

Teachers working with children who are in any way disadvantaged should be specially trained and qualified and should receive commensurate salary and advancement incentives. This is designed to eliminate the still-persisting tendency in some school systems to assign inferior or incompetent teachers to work with disadvantaged, handicapped, or behaviorally

different children, and to practice other forms of covert discrimination which have the effect of increasing rather than reducing disadvantage.

Higher education institutions should develop outreach programs of continuing education and field-based programs of training associated with community service settings. A major focus of these programs should be on upgrading the quality of life of poor and minority groups, and on the prevention of environmentally related retardation.

Minority institutions of higher education are uniquely qualified to deal with problems experienced in minority and poverty settings; therefore, Federal funding activity should take advantage of this expertise and ensure that it is utilized to the greatest possible extent. Minority colleges serving primarily the disadvantaged must receive an equitable share of State and Federal funding. Present statutory provisions requiring equitable funding and affirmative action on personnel practices must be positively implemented.

Objective IV: *Provide adequate controls on the allocation and use of public funds, to safeguard the interests of the populations most at risk from social and economic disadvantage.*

Recommendations:

The Federal Government must assure, within the language of enabling legislation or by *clear designation of legislative intent, how funds are to be allocated* and spent in programs for poor, minority, and handicapped persons, and require demonstration of compliance.

Legislation for health, education, and welfare programs must ensure *proper monitoring and accountability* of programs for people who are mentally retarded, based on outcome criteria in the lives of those served.

Chapter 6 Humane Service Systems

Goal:

Adequate and humane service systems for all retarded persons in need of them.

Objective I: *A comprehensive array of service resources available to meet the essential needs of all retarded persons in all sections of the United States.*

Recommendations:

A minimum array of essential developmental, supportive, and protective services must be guaranteed to mentally retarded persons by Federal action in collaboration with the States, as a first order of priority. Services beyond such minimum levels must be developed and supported on a timely schedule.

Services must be equitable and delivered according to need; provided through public, voluntary or purchase sources, with emphasis on access by choice; delivered by competent manpower selected for its trained capacity to meet service objectives; focused on helping retarded persons achieve the highest possible levels of personal and economic independence.

Interdepartmental policies at Federal and State levels should emphasize *coordinated, simplified, and unified procedures for application and eligibility determination,* so that mentally retarded consumers can get the services they need.

Objective II: *The exercise of free choice and decision by every retarded person or his personal representative in matters that concern his interests.*

Recommendations:

No major decision should be made on behalf of a mentally retarded person except by himself, or by an agent whom he or a duly constituted authority designates to speak for him; this principle must be established by law, regulation, and judicial initiative, and should be assured by HEW, the Department of Justice, and the States.

Administrative procedures of service agencies must reflect the right of the mentally retarded person or his personal representative to select freely any service of his choice for which he is eli-

gible and to express need and demand for those services which his disability requires. This includes the right to coordinate such services for his own unique purposes and to change service agencies at will, as other people normally do. To this end, all Federal agencies and the States should officially recognize this principle through policies, regulations, and affirmative action.

The exercise of meaningful choice or decision requires a basis of *informed participation and consent*. Consequently, all Federal agencies and the States must provide suitable means of guaranteeing mutual understanding on any matter requiring choice and decision affecting a mentally retarded person.

Objective III: *The availability of a personal representative for every mentally retarded person who wishes or requires one.*

Recommendations:

Public policy must assure to every mentally retarded person or his legal guardian opportunity and means to select or employ an agent or agency as his personal representative, to negotiate on his behalf for any available service he requires, no matter how brief or extended his need for service may be. Such policy should be embodied in law and regulation, and must provide for funds or credits to assure to each retarded person the means of free selection of such an agent. The agent or agency selected as a personal representative must be completely independent of any serving agency or system, except that recognition and qualifications for such representative should be established by law.

In order to *stimulate the supply of persons qualified to give competent representation as service brokers to mentally retarded clients*, and to protect against exploitation by unqualified agents, HEW and the States should provide by statute and support for the recruitment, training, and certification of persons with the knowledge and skill necessary to perform this function.

Objective IV: *Maximum opportunity for every mentally retarded person to live in a local community setting of his choosing.*

Recommendations:

Using available legislation, the Federal Government and the States must develop long-range programs so coordinated as to *assure mentally retarded persons an increasing range of choices as to where they shall live*. The choices may vary from independent living to fully protected care, and should be responsive to consumer demand. (See Role of Government, Chapter 9.)

Coordinated with residential alternatives in the local community, there must be developed appropriate, adequate *services essential to help retarded persons remain in homes of their own choice*, including living with their own families, with friends or by themselves.

Restrictive building and safety codes and zoning ordinances must be modified to recognize the degrees of independence and responsibility of retarded persons living in the community.

Central, comprehensive, publicly supported institutions for mentally retarded persons must undergo an orderly process of change from their traditional role as long-term, all-purpose, high-capacity and self-contained organizations to that of care and treatment facilities for specific purposes, with capacity governed by purpose.

States and communities should utilize technical assistance, such as environmental consultant services, involving functional designing principles and flexible design models, for both community and central residential settings for the mentally retarded.

Comprehensive review and continued research should be conducted on the effects of all types of residential service on the development of retarded persons with varying impairments.

Objective V: *Maintenance by all serving agencies of standards of quality and accountability acceptable to the community and to the individual mentally retarded persons being served.*

Recommendations:

A basic code of uniform standards of service for mentally retarded persons should be adopted by Federal departments serving mentally retarded persons, and by the States. The code should consist of fundamental principles directed toward service outcomes, rather than specific and detailed procedures. Substantial observance of these standards must represent a condition for any public financial support for delivery of such services. Waivers should be granted only on specific justification provided by law and regulation. There must be legal, administrative and budgetary provision for enforcement of these standards, and reasonable but limited time for existing facilities to demonstrate compliance.

A workable system for the reporting, storing, codifying, analysis, evaluation and dissemination of *information on service delivery* to mentally retarded persons must be designed and put into operation at the earliest possible time. The resulting information should be disseminated in summary form to the public at large, and regularly updated.

In order to effect quality control, Federal departments serving mentally retarded persons should put into effect a *financial reward and penalty system* applicable to all formula and discretionary grant funds to the States. This system should be responsive to proven ability or failure to provide needed services, maintain quality standards or meet reporting obligations. The system should be based on small but significant increments or decrements in financial support for achievements of or failure to meet obligations.

Every Federal, State, and local program serving mentally retarded persons should be required to make regular evaluations and issue public reports on the *outcomes of service* in relation to financial or social costs. The findings should be based on appraisal of services made by mentally retarded consumers or their personal representatives, by the serving agencies, and by independent judges or evaluating agencies.

Objective VI: *Adequate research maintenance and utilization and manpower development to implement the most effective service delivery possible.*

Recommendations:

Development of a *national study and reference center* on mental retardation and related matters. This center would serve two primary purposes: (a) as a focus of continuous study of the large-scale issues of principle and policy, linking all aspects of the problem toward the achievement of national goals; and (b) as a forum for the continuing intercommunication of all organizations, agencies, groups, and individuals in any way connected with the prevention of retardation or the delivery of services to mentally retarded citizens. Such an organization would be private, non-profit, and independent of unilateral control by any of the specialized groups it might involve.

Active and continuing consolidation, field testing, coordination and *transfer of research findings* on mental retardation to serving agencies and systems, training institutions, and other research centers should be systematically developed. This system should provide, through HEW, regional offices, and other channels, continuing technical assistance to State and local serving agencies and training centers to assure the translation of new knowledge into manpower preparation, pilot service innovations, and long-range service development.

The planning of manpower needs and development should be addressed immediately by HEW in collaboration with the States. Such a plan should (1) develop the means for long-range determination of manpower requirements under the existing

state of the art of service delivery; (2) develop and promulgate long-range manpower development plans for the nation, including provision for new types of manpower as projected programs and future needs determine them; (3) provide for regular modification of these plans to incorporate new knowledge and technical developments; and (4) assure an adequate present and future supply of trained serving agents to meet requirements of adequate and humane serving systems.

In order to carry out the necessary training and preparation of manpower to meet the needs in all parts of the country, HEW should develop a comprehensive program involving the full resources of higher education. *Such a program should be designed to provide adequate manpower development* to meet all the needs of mental retardation in each part of the United States on a long-range basis. It should use all feasible means of developing and utilizing the training resources in the educational institutions of each State and area through consortia, out-reach programs, in-service extensions or other means, in addition to traditional academic degree programs. Universities, public and private colleges, community and junior colleges should all be involved in these efforts, with the role of leadership and coordination designated on a basis appropriate to the characteristics and resources of each area. The scope of manpower concerns falling within this program would be limited only by relevance to the issue of mental retardation and related disabilities. It would range from workshops for the orientation and training of volunteer personnel, through the training of direct care personnel, to professional training of the most advanced nature for administration, research, teaching, and professional service functions.

A significantly expanded effort should be made to *involve large numbers of volunteers* in many areas of service delivery. Volunteers should be recruited particularly among those portions of the population outside the work force, such as older Americans who can be expected to increase in numbers significantly in the next quarter-century. Volunteer services can be developed both to complement and to supplement professional services.

Chapter 7 International Relations

Goal:

The attainment of a high and stable level of international relations in the cooperative resolution of the universal human problems of preventing and ameliorating mental retardation.

Objective I: *Full and continued participation of United States governmental and non-governmental agencies and organizations in international bodies concerned with mental retardation.*

Recommendations:

Many United Nations agencies conduct activities relating to mental retardation, and the UN General Assembly itself adopted a Declaration of Rights of the Mentally Handicapped in 1971, with United States support. The United States, under State Department leadership, should participate actively in furthering such efforts.

The Department of State and other agencies of Government should maintain active interest and participation in the *Inter-American Children's Institute* of the Organization of American States, and support the involvement of U.S. citizens and groups in the activities of this organization related to mental retardation.

The Department of State, HEW, PCMR, and other agencies of government should encourage and support membership and participation of United States citizens and groups in such *non-governmental organizations* as the International League of Societies for the Mentally Handicapped and the International Association for the Scientific Study of Mental Deficiency.

Objective II: *International assistance programs in mental retardation, designed to utilize the developed resources of any country in the organization and operation of mental retardation programs, techniques and personnel training in other countries.*

Recommendations:

The activities of *UN agencies* as the intermediaries for requested assistance.

The *AID programs* of the United States.

Such programs as *"Partners of the Americas"* PREP program, involving relationships between North American universities and those of Latin America; and other relationships fostered by the Organization of American States.

The use of blocks of *Fulbright-Hays Grants* focused on the field of mental retardation.

Short-term intensive *workshops for personal training.*

Short-term intensive *workshops on organizational and operational techniques* in mental retardation programs.

International *exchange of films*, film-strips, and slides with appropriately translated or subtitled explanatory text.

The continued use of *PL-480 counterpart funds* as authorized by Congress on mental retardation projects by agencies of HEW.

Objective III: *Development and maintenance as basic policy of the United States of the international exchange of knowledge and information on all aspects of mental retardation.*

Recommendations:

Participate in the conduct and the reporting of *international scientific seminars* and conferences sponsored by international organizations, universities, scientific and professional associations, and the like.

Encourage and support the *exchange of visiting groups* of professionals, students, and citizens for better understanding of programs and facilities for retarded persons in various countries.

Development of systematic means, under the leadership of the Library of Congress, for the *exchange and translation of significant world literature* in the field of mental retardation.

Development of and support for an *international information system* in mental retardation.

The *International Directory* of Mental Retardation Organizations and Activities—published as a joint venture of PCMR and the International League of Societies for the Mentally Handicapped. This needs to be maintained in a current state by periodic revision.

Facilitation by the Department of State, in cooperation with HEW, PCMR, and other government agencies and professional organizations, of international research projects and seminars on significant problems in mental retardation, with the provision of *supporting funds for organization and travel.*

Chapter 8 Public Attitudes

Goal:

To achieve a firm and deep public acceptance of mentally retarded persons as members in common of the social community and as citizens in their own right.

Objective I: *Advancement of those values which emphasize the worth of every human being without regard to his material possessions, his job status, his productivity, his IQ, or his beauty, and which recognize the importance of diversity and the right to be different.*

Recommendations:

Appropriate attention must be given to the areas of human values, of working with minority cultures, and of dealing with handicaps in the *training of all new teachers*, plus in-service training and the furnishing of curriculum aids in these areas for all present teachers.

All students during the period of elementary and secondary education should be familiarized with the nature of handicapping conditions, both physical and mental, in the context of human values expected in the teaching environment previously discussed.

Implementation of such a value-oriented approach to human relations in the education of children must apply at all levels;

- The *Federal Government* must continue to move forward under the authority of Part D of the Education of the Handicapped Act, which provides not only for the training of special education personnel, but also for the training of regular teachers in knowledge and sensitivity to the needs of the handicapped.

- The States should make training in human values and working with the handicapped a requirement in the *certification* of all teachers, not only of special education teachers.

- *Schools of Education* should develop units on human values and teaching the handicapped as part of the curriculum for all students.

Courses on mental retardation and related disabilities should be included in the curricula of all students of medicine, dentistry, nursing, law and law enforcement, education, religion, psychology, social work, and any other field in which professional practice involves contact with developmentally impaired persons.

The continuation and expansion of the "*education for parenthood*" program is essential, with inclusion of material on mental retardation.

Civic organizations in each community should search for creative ways to *enhance community regard* for the teachers, social workers, recreation leaders, employment counselors, residential aides, and all others who provide supportive service to retarded persons.

ACTION, the National Center for Voluntary Action, and corresponding groups in every community should *intensify the enrollment of volunteers* in activities involving direct contact with retarded persons. In some cases, monetary incentives at least to cover expenses should be used to compensate, as in the Foster Grandparents program; in others, tax credits; and in still others, academic credit in field assignments.

Objective II: *A pervasive feeling of confidence that there will be a sufficiency of jobs, energy and other material goods to support a realistic surge toward humanized values. In that atmosphere, retarded and other handicapped persons will be regarded not as usurping competitors or as a burden or threat, but as needed participants in society, in the work force and in other community activity.*

Recommendation:

Advocates for those who are retarded must *cooperate vigorously in national and local efforts to achieve a society of sufficiency*, and work for a climate of public confidence that such a society is on the way.

Objective III: *Use of changing trends and techniques in communications to promote (a) greater understanding of and appreciation for handicapped persons as neighbors, fellow students, fellow employees, and fellow citizens, and (b) understanding of the means of reducing the occurrence of mental retardation and other handicapping conditions.*

Recommendations:

A continuing program, substantial in size and high in quality, for *educating the general public via all communications media toward acceptance* of retarded and other handicapped persons must be sustained.

A continuing program, substantial in size and high in quality, for *educating the public concerning the causes and means of prevention* of mental retardation is essential.

Every agency or organization concerned with mentally retarded people—national, State or local, public or private—must intensify its own informational efforts and *build a community understanding component into every operating program.*

Chapter 9 The Role Of Government

Goal:

Equitable, coordinated, efficient and effective use of public resources in all mental retardation programs.

Objective I: *Coordinated and comprehensive planning of Federal, State, and local efforts in the area of mental retardation.*

Recommendations:

The Federal Government should establish a continuing interdepartmental planning system on mental retardation, responsible for the preparation and promulgation of short-term and long-range plans. These plans should be based on joint assessment of needs and resources and the commitment of the participating departments to fulfill their respective responsibilities under the plans.

State governments should establish comparable interdepartmental planning systems at the Governors' level, with similar responsibilities for the preparation and execution of plans for mental retardation programs among appropriate State agencies.

The Federal, State, and local governments should guarantee to all programs in mental retardation, whose effectiveness in relation to planned objectives would require an extended period of operation, *assured fiscal resources for the entire period of the planned effort.*

The Federal Government should create a *national information system* on mental retardation through which its departments and the States may get prompt and reliable intelligence on which to base their planning efforts.

Federal, State, and local planning should enlist *consumer panels,* representing mentally retarded individuals themselves as well as their families and other representatives. These panels should be invited to participate in planning activities so as to assure that planning correctly reflects the interests of those persons for whom it is undertaken.

Objective II: *Assure, through Federal, State, and local organization and leadership, that program activities involving joint participation of two or more agencies serving mentally retarded persons will be planned and conducted in a coordinated and collaborative way.*

Recommendations:

There should be established in each major department which provides services in relation to mental retardation, the position of an *advocate, responsible to advise the department administrator* of problems observed in the coordination of agency program efforts, to initiate efforts to resolve conflicts and effect solutions, and to call attention to program resources and authorities which may not be fully utilized in the best interests of those being served.

Federal departments should, through bilateral or multilateral agreements, develop routine means to *identify and resolve conflicts in policy,* reflected in proposed or enacted law, proposed regulations, and instructional materials, which may result in one program's operations interfering with the realization of benefits from another.

Each major department providing services should provide a *casefinding and access program* to inform all known mentally retarded persons about services to which they are entitled, and guide them to sources of help in a fashion that assures they are actually offered such help.

Objective III: *Federal, State, and local accountability for the provision of effective services to mentally retarded consumers in an efficient manner and with due regard for the consumer's rights of redress.*

Recommendations:

Federal, State, and local agencies should require of all case services provided or funded with their assistance, including those provided by private agencies, that a *mutual agreement for the service* and the purpose which it is to meet be negotiated with each person served, and that the degree of fulfillment of such agreements form one basis of determining the effectiveness of service. The confidentiality of such records must be safeguarded.

Federal, State, and local agencies responsible for providing or funding services should establish systems for *periodic monitoring* of program achievements and case benefits, and for evaluating them against both program and fiscal standards.

A prompt administrative appeals procedure should be offered by all Federal, State, and local agencies responsible for providing or funding services. If a mentally retarded person or his representative feels that he is not receiving services in accordance with his express need, he should be able to count on an impartial review and on an appropriate and prompt remedy.

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